Juvenile Idiopathic Arthritis in two Tertiary Centres in the Western Cape, South Africa

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Declaration

I, ……, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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1. Protocol

(Submitted to School of Child and Adolescent Health UCT before commencement of the study)

1.1. Introduction

Juvenile idiopathic arthritis (JIA) is defined as arthritis of unknown aetiology that begins before the 16th birthday and persists for at least 6 weeks, other conditions being excluded. It has become a well defined and classified disease with the revised International League of Associations for Rheumatology (ILAR) classification in Edmonton in 2001. [1]

As JIA is a disease with serious functional implications, a descriptive study would not be complete without reviewing both the functional and clinical parameters of the disease.

Juvenile idiopathic arthritis has been poorly researched the South African context. A descriptive study was done in 1984 about JIA specifically in South African children of black and indian descent[2]. It was a retrospective study of 60 patients from the R K Khan Hospital complex in Durban, South Africa, using the old WHO/EULAR classification. There have been numerous descriptive studies done in countries throughout the world, including westernised countries such as the USA[3] and Britain[4] as well as studies in developing countries such as Turkey[5], Morocco[6] and India[7]. These will all be vital for comparing data to our study population.

From a functional perspective, a recent study in 2009 looked at describing JIA in Moroccan patients[6]. The study described health related quality of life (HRQOL), functional disability, using the child health assessment questionnaire (CHAQ) as well as types of JIA, clinical determinants and laboratory parameters. A recent multinational study by the Paediatric Rheumatology International Trials Organisation (PRINTO) compared HRQOL and functional disability (using CHAQ) from 3 geographic areas, including 16 Western European Countries, 10 Eastern European countries and 4 Latin American countries[8].

From, the above, it is clear that there has been a lot of recent work into describing JIA in both developed and developing countries in terms of clinical disease, HRQOL and functional disability. There has been very little African data, however, on this subject.

1.2. Objectives

To describe the functional disability and clinical disease characteristics in a sample of children diagnosed with JIA in Cape Town, South Africa.

1.3. Methods

1.3.1. *Study Design*

This is a prospective cross sectional study.

1.3.2. *Subjects*

Subjects will be from Groote Schuur Hospital Rheumatology clinic (Please see amendment 1). These are newly referred as well as previously diagnosed and followed up patients

from the Cape Town area. This clinic serves the population of the Western Cape region of South Africa and also acts as a tertiary referral area to other large regions of South Africa such as the Northern and Eastern Cape. It is thus a large area of South Africa representing a culturally diverse population.

Patients will be randomly sampled from the clinic attendees.Patients should be younger than 16 when diagnosed with Juvenile idiopathic arthritis as well as classified by a paediatric rheumatologist into an ILAR 2001 subtype.(Appendix 1)

1.3.3. *Measurement*

Functional disability is assessed using the CHAQ[9; 10] which has been used in both the Moroccan[6] study as well as the PRINTO[8] series and is thus a well validated questionnaire in both developing and developed worlds. It would be useful in comparing data from these studies.

The CHAQ has been translated into Afrikaans, English, Zulu and Xhosa, some of the 4 main languages of the area. The mother or child (when capable) would be asked to fill out the CHAQ with the help of the doctor or nurse attending to them at the clinic. The CHAQ measures the child's ability to perform functions in 8 areas (dressing and grooming, arising, eating, walking, hygiene, reach, grip and activity) for a total number of 30.Each question is scored from 0 to 3 (0 = no difficulty, 1 = some difficulty, 2 = much difficulty, 3 = unable to do so). The question with the highest score determines the score for that functional area. If aids or devices are used or help is needed to complete tasks in a certain area, a minimum score of 2 is recorded for the corresponding functional area. The scores

for each of the eight functional areas are averaged to calculate the CHAQ disability index (DI), which ranges from 0 to 3 (0 = best; 3 = worst). The parent's version of the CHAQ incorporates also a doubly-anchored horizontal 10 cm visual analogue scale (VAS) for the assessment of the child's overall well-being(parent general evaluation-PGE-with anchors of '0 = very well' and '10 = very poor') and a doubly-anchored horizontal 10 cm VAS for the assessment of the intensity of the child's pain (with anchors of '0 = no pain' and '10 = very severe pain'). [5]

On a separate excel spreadsheet (appendix 5) for each patient there is a record of study number, age (0-16), sex (M/F), primary caregiver (mother/father/grandparent/aunt etc), age at diagnosis, area of residence (suburb/township) and level of schooling (Grade 1-12). Importantly, there would also be a record of whether the child had ever had TB or HIV. There would be a diagram where one could record involved joints including active (swollen or limited and tender) and limited joints (joints with a limited range of motion).(Appendix 6). There would also be a place for the recording of laboratory results (if available), namely anti nuclear antibodies (ANA), rheumatoid factor (RF), human leukocyte antigen B27 (HLA B27), haemoglobin (Hb), platelets (Plts) erythrocyte sedimentation rate (ESR), C-reactive protein (CRP), the liver transaminases- ALT and AST, and creatinine.

1.3.4 Investigators

Investigators would include doctors and nurses in the rheumatology clinic at Groote Schuur Hospital.

1.3.5 Ethics

Each patient will be allocated a study number and therefore will have their confidentiality protected. No additional tests or interventions will be performed on patients for the purpose of the study. Informed consent will be obtained by parents, or where capable, patients.

1.3.6 Reporting and implementation

The finalised documentation and data will be presented to School of Child and Adolescent Health Research Committee for evaluation and submission to publication, if accepted.

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2 Protocol Amendment 1

(Submitted to School of Child and Adolescent Health)

Please be advised that this protocol will also be submitted to Stellenbosch University Ethics Committee to seek approval for the collection of data from the Tygerberg Hospital Paediatric Rheumatology Clinic which is attended by the study supervisor Dr Chris Scott. Should the Stellenbosch Ethics Committee approve, the data collected will be used with the data from Groote Schuur Hospital for the purposes of the study. The initial protocol, approved by the school of child and adolescent health, only specified that data from Groote Schuur would be collected.

Dr K Weakley

Principal Investigator

3 Literature Review

3.1 Objectives of literature review

The objective of this study is to describe the functional disability and clinical disease characteristics of Juvenile Idiopathic Arthritis (JIA) in a sample of children diagnosed with JIA in Cape Town, South Africa.

The main objectives of this literature review is to

Identify studies that would be useful in comparing South African data to other cohorts

To assist in finding validated variables and scores which have been standardly used to assess the type, functional outcome and severity of JIA.

JIA is a poorly described disease in an African context, so recent work from other developing countries is valuable in assessing South African data. Standardised, validated variables are needed to ensure quality data collection that can be meaningfully compared to international data.

3.2 Literature Search Strategy

An internet search, using pubmed was undertaken. Phrases searched were Juvenile Idiopathic Arthritis AND functional disability OR disease characteristics. This search selected 44 articles. A separate search was done for Juvenile Idiopathic Arthritis AND classification.

Inclusion criteria for previous patient based studies were

Studies with at least 30 subjects

Studies that, despite their objectives described

The type of JIA

AND

Clinical characteristics

OR

Functional disability

OR

Laboratory parameters

OR

Other relevant information such as age at onset, joints involved, pain and general wellbeing.

To summarise, the most basic study that was accepted would need to have a group of type-classified patients with JIA. Classification of JIA is difficult as there is only recently a well accepted international classification, so both old ACR (American College of Rheumatology)[1] and EULAR (European League Against Rheumatism)[1] were excluded and the recent ILAR (International League of Associations for Rheumatology)[6] classification

was accepted. The only exception was a South African study done in 1984 which uses the EULAR classification but was the only South African data found, so it was included.

There was also no time limit set on publication of studies, but obviously more recent and larger studies were favoured when the most relevant literature was selected.

3.3 Literature

3.3.1 Definition

The first necessary step is a definition of JIA. There has been a history of difficulty on this subject. In 1977, two sets of classifications were formulated, the European criteria (European League against Rheumatism, EULAR)[1] for Juvenile Chronic Arthritis, and the North American Criteria (American college of Rheumatology, ACR) for Juvenile Rheumatic Arthritis[2]. Both systems used age criteria as 16 years and below, the EULAR included spondyloarthropathy and required the disease to be present for 12 weeks, the ACR did not include spondyloarthropathy and required the disease to be present for 6 weeks only.[3]

In many of the early descriptions of JIA, therefore the two different names and criteria are used. One classification totally excluded the subgroup of patients with spondyloarthropathy (now known as enthesitis related arthritis).

In 1995, the first international classification was formulated with an amendment in 1997[4;5]. The most recent classification is the International League of Rheumatology (ILAR) classification in 2001 at Edmonton[6.] This classification defines JIA as arthritis of unknown

aetiology that begins before the 16th birthday and persists for at least 6 weeks, other conditions being excluded.

It classifies JIA as

Systemic Arthritis

Oligoarthritis

Polyarthritis-rheumatoid factor negative

Polyarthritis- rheumatoid factor positive

Psoriatic arthritis

Enthesitis Related arthritis

Undifferentiated arthritis

This classification has been widely used, and found to be easy to use and transparent in an evaluation published in 2005[7].

3.4 Studies describing JIA

Below are summaries of the most relevant articles

3.4.1 Morocco [8]

This is a cross sectional study that recruited 80 patients with JIA according to ILAR criteria, over 18 months. The aim was to assess health related quality of life and its' determinants in children with JIA. Patient demographics, type of JIA, clinical determinants, such as

visual analogue scales(VAS) for pain and parent general evaluation (PGE) and lab parameters were obtained. Each patient also had a childhood health assessment questionnaire(CHAQ) to assess functional disability as well as a juvenile arthritis quality of life questionnaire (JAQQ) . There were only a few enthesitis related arthritis (ERA) and psoriatic arthritis patients, so the categories were excluded from further consideration.

All patients were classified according to ILAR but in the results there is no differentiation between rheumatoid factor(RF) positive or negative polyarthritis patients, they are just counted together as polyarthritis.

It was found that disability was higher in adolescents and in patients with polyarticular and systemic subtypes as opposed to oligoarticular. Health related quality of life was significantly associated with CHAQ score, JIA subtype (worse in polyarticular and systemic subtypes), female sex and number of joints with limitation.

This is a very useful study for the purpose of this literature review. Most importantly it is a study from a 3rd world context in an African country. Obviously, it has a different objective, but a lot of the same data has been collected. The subtypes, as well as age of onset, ESR and CHAQ can all be used to describe JIA as well as functional disability. There is no mention of whether variables are normally distributed, but the numerical variables are expressed as means. The findings have been summarised in table 1. below.

3.4.2 Childhood Arthritis Prospective Study (CAPS)-UK [9]

This study is a prospective longitudinal inception cohort study which aims to provide information on the long term outcome of children with JIA following routine care in the UK. In 2010, an analysis was published with the aim to describe the outcomes of children 1 year after 1st presentation to paediatric rheumatology and to identify factors that predicted moderate to severe disability at 1 year.

The CAPS study has been recruiting since 2001. Eligibility includes children aged 16 or less presenting to one of five paediatric rheumatology referral centres with a new diagnosis of inflammatory arthritis. Demographic data and medians of joint count, CHAQ, PGE, VAS and ESR are collected at first presentation and then again at 6 and 12 months.

This study is the largest prospective report of early outcomes in a cohort of children with JIA. It was concluded that after one year of presentation the majority of children will have significant improvement in pain, joint inflammation and disability. Some children, however, continue to have moderate to severe levels of disability and predictors of these were higher levels of CHAQ at baseline, higher PGE scores and female gender.

Although this study has different aims to what the current proposed study does, it is a large, well constructed study that looks at variables and characteristics that describe the functional disability and disease characteristics in this group. Strict and meticulous use of ILAR classification, and use of PGE, VAS, ESR and CHAQ make it a valuable study for comparison.

The main issue however is that the current study will be a prospective cross sectional study that enrols patients once at a random clinic visit. Therefore, the data will not be longitudinal, with some patients being first presentations and some being many years into treatment. For these reasons, in the table below, data from the 1 year follow up cohort has been summarised. This is however a limitation to how much the two data subsets can be compared.

3.4.3 Turkey [10]

In 2008, a descriptive study was published from Turkey. The aim was very similar to the current study in that clinical and laboratory features of JIA in Turkish children were evaluated. A total of 196 patients were included in a retrospective record review. ILAR subtype, age, gender, ANA, HLA B27 and Rheumatoid factor (RF) results were collected. This study was descriptive and did not look at functional disability, general wellbeing or pain evaluation. It was found that there is a very different profile to JIA in western countries. There were higher rates of polyarticular JIA, higher rates of male JIA and lower rates of ANA positivity.

This clinical data is very useful for comparing the Western Cape population as it is data from a non-western country and is descriptive and well classified according to ILAR classifications.

3.4.4 *Paediatric Rheumatology International Trials Organisation (PRINTO) multinational trial* [11]

Any literature review would not be complete without including the large PRINTO series. This is a collaborative multicentre study that enrolled 3167 patients with JIA, and 3123 healthy patients from 30 countries. Countries were divided up into regions as illustrated below.

Western Europe-Austria, Belgium, Denmark, Finland, France, Germany, Italy, Greece, the Netherlands, Norway, Portugal, Spain, Sweden, Switzerland, UK and Israel

Eastern Europe-Bulgaria, Croatia, Czech Republic, Georgia, Hungary, Latvia, Poland, Russia, Slovakia and Serbia-Montenegro

Latin America-Argentina, Brazil, Chile and Mexico

The aim was to compare health related quality of life and to identify clinical determinants for poor health related quality of life in patients with JIA from the above geographical areas. CHAQs were translated into multiple languages, and used to assess functional disability. Active joint count, limited joint count, PGE, VAS and ESR were evaluated in each patient. Children were classified according to the ILAR classification. Interestingly, in the results, there is no differentiation between polyarticular RF positive and polyarticular RF negative patients. Enthesitis related arthritis as well as psoriatic arthritis patients were not included as there were very few patients.

The results of the study indicate that patients with JIA have a significant impairment of their health related quality of life compared to healthy peers. Disability and pain are the most important determinants of physical and psychosocial wellbeing irrespective of geographic area of origin. It was found that children from Eastern Europe and Latin America experienced a more severe disease, had a lower frequency of systemic disease, less female predominance and generally presented later than children from Western Europe.

This is therefore a very useful study as it provides a lot of data describing the disease in developed and developing areas. It also confirms that the measurements used are useful for extrapolating the quality of life of patients, irrespective of area of origin.

In table 1. below, results have been summarised based on the 3 geographical areas mentioned above. Means are used in this data to describe categorical variables, but no specification of whether data is normally distributed or not is given.

3.4.5 India [12]

A longitudional cohort study was recently published from India which classifies and describes a cohort of Indian patients very well. The aim of the study was to describe a cohort of patients, as well as compare the ILAR classification system with the ACR[2] and European Spondyloarthropathy Study Group classification systems[13].

235 patients were reviewed over 11 years, and classified, very thoroughly into ILAR subtypes. From 1999, patients were recruited, classified into subtypes and followed in a

longitudinal cohort. Clinical details, and investigation profiles for the first year of disease were recorded.

It was found that enthesitis related arthritis(ERA) was the most common subtype. The frequency of RF positivity was unexpectedly high. The incidence of ANA positivity was strikingly low, although they did use the ELISA testing method which has been shown to detect fewer ANA in children with JIA than Hep 2 immunofluorescence[17]. A high level of RF positivity was found in children classified as undifferentiated arthritis. It was also found that 16% of children that did not classify as ERA (either female or age less than 6 years old) in the polyarticular and oligoarticular subtype tested positive for HLAB27. They therefore questioned the value of HLA B27 and RF testing in India to determine ILAR classification.

The authors noted limitations to the study that are related to challenges similar to the South African context. It was difficult to accurately determine onset of disease, due to poor patient recall and insufficiency of early records. Several of the children lived in poorly resourced, rural communities and they had to exclude some patients as they only had had one RF study. As they mention, a Nordic study done recently shows that less than 50% of cases of polyarthritis and less than 35% of cases with oligoarthritis could actually achieve 2 RF tests as specified by the ILAR classification system[18].

This study does not describe the disease characteristics or functional outcome but does provide good data from another 3rd world perspective. It shows that JIA in India has a very

different profile to other countries, with very high rates of ERA. It also highlights some of the difficulties of the ILAR classification in a developing, under resourced setting.

The methods of the various studies are summarised in the table 1. below

Table 1

Study	Setting	Method	No. Patients	Time period
Morocco[8]	Tertiary	Cross sectional prospective	80	18 months
UK[9]	Tertiary	Longitudional inception cohort	740	1 year
Turkey[10]	Tertiary	Retrospective record review	196	
PRINTO[11]	Tertiary	Multicentre case control cross sectional	3167	
India[12]	Tertiary	Longitudional cohort	235	11 years

Table 2 Results of various studies: values are expressed as medians unless * indicates a mean value

Study	Morocco		UK		Turkey		Printo W. Europe		Printo E. Europe		Printo Latin America		India	
N	80		740		196		2102		668		397		235	
Age current	10.85*		7.6		8.8*		9.4*		6.8*		10.7*			
Age at onset	7.53*		6.6		6.8*		5.4*		11.4*		6.6*		12	
Female	47	59%	476	64%	94	47%	1484	83%	428	72%	255	68.3%	98	41.7%
Systemic	21	26%	42	6%	30	15.3%	345	16.4%	155	23%	113	28.5%	19	8%
Poly RF+	25	31.5%	23	3%	13	6.6%	686	32%	222	33%	161	40.6%	28	12%
Poly RF-	NA	NA	148	20%	60	30.6%	NA	NA	NA	NA	NA	NA	41	17%
Oligo Persistent	30	37,5%	353	48%	48	24.4%	620	29.5%	211	31.6%	87	21.9%	39	17%
Oligo extended	4	5%	32	4%	19	9.6%	451	21.5%	80	12%	36	9%	10	4%
ERA			51	7%	19	10.3%							84	36%
Psoriatic			61	8%	2	1%							3	1%
Undifferentiated			30	4%	5	2.5%							11	5%
VAS pain(mm)	28.4*		9				28*		23*		27*			
VAS general(mm)			6				25*		28*		24*			
Limited joints	1.78*		0				5.9*		8.6*		10.1*			
Active joints	4.39*		0				5.3*		6.7*		7.1*			
CHAQ	0.84*		0.25				0.7*		0.6*		0.8*			
ESR	28*		9				30.7*		27.7*		31.2*			

3.4.6 The South African Context

As far as could be found in this data search, there has only been one study done that describes disease characteristics of juvenile arthritis in South Africa. It is a study done in Durban in 1984. The aim was to evaluate Indian and Black children with juvenile chronic arthritis[14]. It was a retrospective review of Black and Indian children between the ages of 1-16 who fulfilled EULAR criteria[1] for the diagnosis of juvenile chronic arthritis. 60 patients were studied, of whom 42 were Black and 18 of Indian descent.

The results showed similar data to the Indian and Turkish populations described above. A predominance of polyarticular arthritis and a relatively low occurrence of pauciarticular arthritis was found. It was noted that there was a high occurrence of rheumatoid factor positivity, a low level of ANA positivity and an equal female to male ratio. The results are summarised below, in table 2.

Notable, any enthesitis related or spondyloarthropathy type arthritis as well as psoriatic type was not included.

This is a relatively small study which currently has limitations on its' usefulness due to use of the old classification criteria, but it was the only study found, that attempts to describe juvenile arthritis in a South African population. Some of the results are summarised below.

Table 2

Mode of Onset	no	%	Black		Indian		Presence of rheumatoid factor	
Systemic	9	15	6	14%	3	16%	4	44%
Polyarticular	29	48.3	21	50%	8	44%	13	44.8%
Pauciarticular	22	36.7	15	35.7	7	39%	5	22.7%

3.5 Limitations to literature review

All of the above mentioned studies have been done in a tertiary hospital setting. This may skew results in 2 ways. Patients who attend a paediatric rheumatology clinic may have more severe disease than those in the community with milder disease. These milder forms have a higher likelihood of going into remission and may never make it to tertiary centres. Firstly, this may cause a skewed perception that JIA in an area is more severe than it may actually be.In addition, the subtypes causing the most severe disease will be most likely to attend a specialised clinic and therefore, skew the relative proprtions of disease subtypes for that area.

The literature review also highlights that the studies have different methodologies and therefore make meaningful comparison difficult.

3.6 Conclusion

The main objective of this literature review was to

Find studies that would be useful in comparing South African data to other cohorts and

To assist in finding validated variables and scores that have been standardly used to assess the type, functional outcome and severity of JIA.

The above literature should show that these objectives have been met. A number of recent and relevant studies have been quoted. They are from a wide range of different geographical areas and population subtypes. These show that JIA is a well described disease with a lot of recent work having been done to standardise and globalise the classification. JIA is also a disease that has a different clinical picture in differing regions and population groups. It highlights that there is very little work done in describing JIA in African population groups, specifically the South African population. This literature review has been helpful in determining standard variables that are used to assess JIA. CHAQ is a universally used as a tool for assessing functional disability in the above studies. Clinical determinants that are often used are VAS, PGE and joint counts. ESR is useful in determining severity of JIA.

The literature review is therefore useful in finding tools to achieve the aim of the current study, which is to describe clinical characteristics and functional disability in the Western Cape of South Africa.

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4 Journal article

4.1 Abstract

Background. JIA is a disease that shows wide variations between differing populations. Due to recent international consensus on classification criteria, JIA has been widely described in many countries and population groups. There has been almost no data that describes JIA in an African, specifically Sub-Saharan African setting.

Objective. To describe disease characteristics and functional disability in two tertiary centres in the Western Cape, South Africa

Methods.86 children were recruited during random clinic visits to rheumatology clinics at Tygerberg and Groote Schuur Hospital between April 2010 and April 2011. Children were diagnosed using International League of Associations for Rheumatology (ILAR) 2001 classification criteria. Consent was obtained, medical records examined, Childhood Health Assessment Questionnaires (CHAQ), visual analogue scales (VAS) for pain and general wellbeing were completed and all children were examined by a researcher in conjunction with a paediatric rheumatologist. HIV status as well as tuberculosis disease and treatment were investigated.

Results. A total of 86 children were enrolled. 8 children were excluded (2 HIV arthropathy, 1 TB arthritis, 1 SLE, 4 insufficient data) leaving a total of 78 patients. There was an equal female to male ratio-39 males and 39 females. There were 6 systemic JIA (7.69%), 17 oligoarthritis (21,79%), 11 polyarthritis rheumatoid factor (RF) positive (14.10%), 21 polyarthritis RF negative (26.9%), 1 psoriatic arthritis (1.28%), 18 enthesitis related arthritis (23%) and 4 oligoextended JIA (5.12%). The median CHAQ for the group was 0.5, the median VAS for pain was 18mm and median VAS for general wellbeing was 25mm. Kruskal-Wallis equality-of-populations rank test showed significant differences ($p<0.05$) between CRP, ESR, number of active joints and limited joints between subtypes.

Conclusion. JIA in the Western Cape of South Africa has a very different profile to JIA that has been described elsewhere. Disease subtypes, specifically enthesitis related arthritis and polyarthritis are more prevalent. There are unique challenges in this setting, with differing disease course, later presentation and different disease characteristics.

4.2 Introduction

Juvenile idiopathic arthritis (JIA) is a poorly described disease in South African children. According to International league of Associations for Rheumatology (ILAR)[1], it is defined as arthritis that begins before the 16th birthday and persists for at least 6 weeks, other conditions being excluded. In 2001 at Edmonton, the ILAR proposed a standardised definition and classification of JIA. This classification has, in recent years, been used all over the world to describe disease characteristics in various populations and nationalities. Included in these recent studies are large multicentre trials[2;3] and smaller studies from both developed and developing countries[4;5;6].

South Africa is a country that is poorly resourced in the field of Paediatric Rheumatology. There are few centres with recognised paediatric rheumatologists in South Africa. There has only recently been training positions for paediatric rheumatologists and funding for these positions remains a problem. Children with paediatric rheumatological diseases, specifically JIA, have therefore been treated by general paediatricians, general practitioners, adult rheumatologists, or gone untreated. In South Africa, there is also a high burden of infectious diseases (HIV, TB) as well as social diseases (poverty, malnutrition). These diseases demand a great amount of attention and resources, and therefore the amount of research into rheumatological diseases such as JIA has been very limited.

JIA is a disease with severe implications for patients and families. Function and quality of life can be severely affected[7]. JIA is an important cause of short and long term disability[19] and is the most common rheumatological disease in children[8].

Studies in developed countries have estimated a prevalence of JIA that varies between 0.07[20]-4[21] per 1000 children[8].There is very little consensus on the exact prevalence of JIA. As evidence increasingly shows, it is clear that JIA prevalence is underestimated. The best studies to approximate prevalence are those that involve large numbers of children in homes or schools with a history and examination done by an experienced rheumatologist[8]. Clinical case studies produce relatively lower prevalence due to non-diagnosed or misdiagnosed cases in the community[8]. In the South African setting, there is relatively poor access to healthcare, complex economic migration and large socioeconomic discrepancies. Therefore these studies are extremely difficult and no accurate prevalence figures are available for South Africa.

JIA is a disease that shows variation in expression between different ethnicities[9].There is substantial interest in the differences in JIA in various parts of the world and various population groups.[2;3;5]

Many studies have been done recently to describe JIA as per the new, standardised ILAR classification. The Paediatric Rheumatology International Trials Organisation(PRINTO) recently performed a study of 3167 patients from 3 large geographical areas (Western Europe, Eastern Europe and Latin America)[2] . Over the last 10 years, studies have been done in UK[3] , Morocco[4] , India[5], Turkey[6], and Japan[10] which describe various aspects of the

disease including health related quality of life, classification, disease activity, functional disability, clinical and laboratory features. A drawback is that many of these studies are based at tertiary centres, and may not have similiar methodology or objectives. This makes true epidemiological inferences of JIA difficult. These studies do serve to highlight what may be geographical differences in JIA presentation.

The only South African literature to describe disease characteristics of JIA, that could be found, was a study done in the Kwazulu Natal region of South Africa in 1984[11].Black and Indian children were specifically included only and patients were classified according to the 1977 European League Against Rheumatism criteria[22] for juvenile chronic arthritis. This classification divided JIA into polyarticular, pauciarticlar and systemic subtypes only. A predominance of polyarticular JIA and and equal male to female ratio among patients with juvenile chronic arthritis was described. This study was the only study to describe JIA in South Africa in the last 30 years. Unfortunately it's usefulness now, is limited by the use of the old European classification.

Cape Town is an area with a unique population profile in terms of ethnicity and race. The population of children (0-17years old) in Cape Town is 1.7 million [17]. Of these children approximately 34.9% are black african, 44% are coloured, 1.8% are asian and 19.3% are white[15].

Cape Town is a diverse city with 2 tertiary hospital centres. The first is Groote Schuur Hospital which is the academic hospital associated with the University of Cape Town, and the second is Tygerberg Hospital which is associated with Stellenbosch University. Both of

these hospitals service the Western Cape of South Africa as tertiary referral centres and both have a paediatric rheumatology clinic and collaborate with each other.

The aim of this study, therefore is to describe the disease characteristics and functional disability in a sample of children from 2 tertiary centres in Cape Town, South Africa.

4.3 Methods

4.3.1 Setting

Patients were recruited from the Groote Schuur and Tygerberg Hospital Paediatric Rheumatology clinics between March 2010 to April 2011.

4.3.2 Participants

Participants were patients attending the above clinics who were diagnosed with Juvenile Idiopathic Arthritis as per ILAR 2001 definition. Patients were recruited at random visits when a researcher was available. No limitation was set on whether it was the patients' initial or ongoing visit.

4.4 Procedures

4.4.1 Data Sheet

A researcher collected patient data on a data collection sheet (appendix 6). This data included

-Age at diagnosis and current age

-Sex

-Type of arthritis

-Blood results- C-reactive protein(CRP), erythrocyte sedimentation rate (ESR), -haemoglobin (HB), platelets (plt), antinuclear antibodies (ANA), rheumatoid factor IgG (RF), human leukocyte antibody B27 (HLA B27), alanine transaminase (ALT), aspartate transaminase (AST). Blood was not taken for the purpose of the study, only as part of ongoing patient care. It must be noted that the majority of ANA blood tests were done were ELISA tests as HEp 2 immunofluoescent ANA studies are only available at Tygerberg Hospital.

-Previous HIV test results and whether or not the child is on antiretroviral drugs.

-Previous diagnosis or current diagnosis of tuberculosis as well as current or previous treatment

4.4.2 Childhood Health Assessment Questionnaire

(Appendix 2, 3, 4, 5)

A childhood health assessment questionnaire (CHAQ) was filled out by the parent, or when capable, the child. The CHAQ measures the child's ability to perform functions in 8 areas (dressing and grooming, getting up, eating, walking, hygiene, reach, grip and activity). Each question is scored from 0 to 3 (0 = no difficulty, 1 = some difficulty, 2 = much difficulty, 3 = unable to do so). The question with the highest score determines the score for that functional area. If aids or devices are used or help is needed to complete tasks in a certain area, a minimum score of 2 is

recorded for the corresponding functional area. The scores for each of the eight functional areas are averaged to calculate the CHAQ disability index (DI), which ranges from 0 to 3 (0 = best; 3 = worst). The parent's version of the CHAQ incorporates a doubly-anchored horizontal 100mm visual analogue scale (VAS) for the assessment of the child's overall well-being (with anchors of '0 = very well' and '100 = very poor') and a doubly-anchored horizontal 100mm VAS for the assessment of the intensity of the child's pain (with anchors of '0 = no pain' and '100 = very severe pain')[2].

The CHAQ is a well validated international tool and has been used in many recent trials[12] . The CHAQ was translated into Zulu, Xhosa and Afrikaans for the purposes of this study. Unfortunately these translations have not been formally validated.

4.4.3 Joint Count

(Appendix 7)

All participants were then examined by a researcher in conjunction with a paediatric rheumatologist and a joint count was done and recorded on 2 joint diagrams- one for limited joints (limited range of movement) and one for active joints (swollen or limited and tender)[1].

4.5 Analysis

Data was collected into a Microsoft excel spreadsheet using a number assigned to each patient. Categorical variables were assigned numerical codes. The data was then analysed using STATA software and a number of statistical tests were applied. A Shapiro Wilks test was done on each numerical variable for the whole sample, and for each variable per type. If p value was >0.05 data was presumed to be normally distributed. Median and mean values were obtained. Categorical values are expressed in absolute frequency and percentage. Kruskal-Wallis equality-of-populations rank tests were performed to assess if there were significant differences in numerical variables per subtype of JIA.

4.6 Ethics

Ethics approval was granted by the University of Cape Town and Stellenbosch University ethics committees respectively. All parents and, where possible, capable children (age over 16) were given consent forms prior to enrolling in the study and had all procedures explained to them. It was clearly explained that should the patients not wish to participate in the study, it would not affect their ongoing care. No additional blood tests/procedures or radiological tests were done for the purposes of the study. Confidentiality was ensured for all participants.

No conflict of interest was declared. This study was done by Kate Weakley for the purposes of an MMed and no funding was necessary. Any stationary/transport costs were

minimal and covered personally by the researcher. Patients were not paid for their participation or offered any incentive.

4.7 Results

A total of 86 children were enrolled in the study.

4 patients were excluded due to insufficient clinical data collection. Of these, 1 patient with oligoarthritis had an insufficient clinical examination recorded; 1 patient with oligoarthritis had an incomplete consent form and 2 patients (1 polyarthritis, 1 oligoarthritis) had blood results that could not be traced. 2 Children were diagnosed with HIV related arthritis and excluded. 1 child initially had arthritis and then developed SLE, so was excluded and 1 was later diagnosed with tuberculosis(TB) arthritis so was excluded. Therefore 8 children were excluded leaving a total of 78 patients.

There was an exactly equal female to male ratio-39 males and 39 females. Mean age at diagnosis was 7.31 years of age (95% CI 0.93). Mean current age was 12.40 years old (95% CI 1.28). Out of these, there were 6 systemic JIA patients (7.69%), 17 oligoarthritis patients(21,79%), 11 polyarthritis rheumatoid factor (RF) positive (14.10%), 21 polyarthritis RF negative (26.9%), 1 psoriatic arthritis (1.28%), 18 enthesitis related arthritis (ERA) (23%), 4 oligoextended JIA (5.12%). See Table 1 and figure 1.

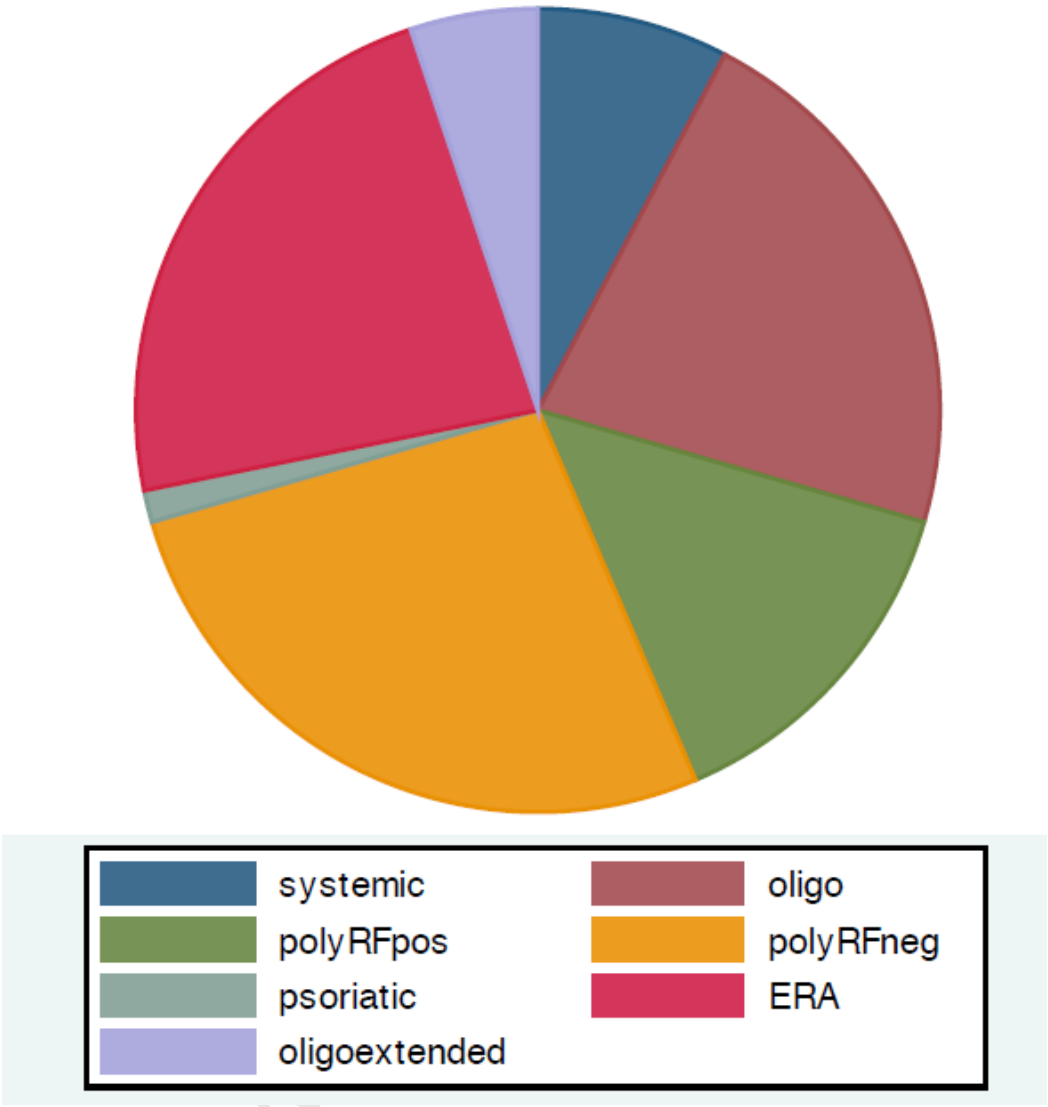

Figure 1

Table 1

	Systemic	Oligo	PolyRF+	PolyRF-	Psoriatic	ERA	Oligoextended
no	6	17	11	21	1	18	4
%	7.69	21.79	14.10	26.90	1.28	23	5.12

Table 2-*Variables per type. All values are expressed as medians as they show non normal distribution overall. If the variable was normally distributed within a subtype, the mean is given in brackets.*

Type	CHAQ	Pain VAS (mm)	General VAS (mm)	Active Joints	Limited Joints	ESR
Systemic	0.437(0.875)	10.5(14.8)	12(23.3)	3(5.66)	0	58.5(65.5)
Persistent oligo	0.375	19	23	1	1(1.17)	9
Oligo Extended	0.563(0.59)	21(28.2)	34.5(35.7)	5.5(5.5)	4.5(4)	5(6)
Poly RF+	1(1.05)	20(32.2)	30(30.8)	3	9	42(40.9)
Poly RF-	0.875(1.12)	21(27.8)	27(31.2)	2	6	12.5
ERA	0.125	14	14	1	1	12
Total	0.5	18	25	2	2	14

Each subtype had a mean CHAQ, pain VAS, General VAS, active joint count, limited joint count, ESR and CRP, as can be seen in table 2 . Shapiro Wilks testing for normality was done on all variables for the total cohort as well as per type. For the total cohort, all of the variables had p values <0.05 and were therefore not normally distributed. Therefore, in table 2, the values are given as medians, even though within some subgroups values may have been normally distributed. The values in brackets are mean values where that variable was normally distributed within that type as evidenced by a Shapiro Wilki test with a p value >0.05. As there was only 1 psoriatic arthritis patient, it has been excluded from this table.

The Kruskal-Wallis equality-of-populations rank test showed significant differences ($p<0.05$) in CRP, ESR, number of active joints and limited joints between subtypes. Limited

Joints p=0.0003, Active Joints p=0.0013, CRP p=0.0061, ESR p=0.003. See figures 2,3 and 4 below.

ESR vs. Type

ESR showed significant differences within type p=0.003

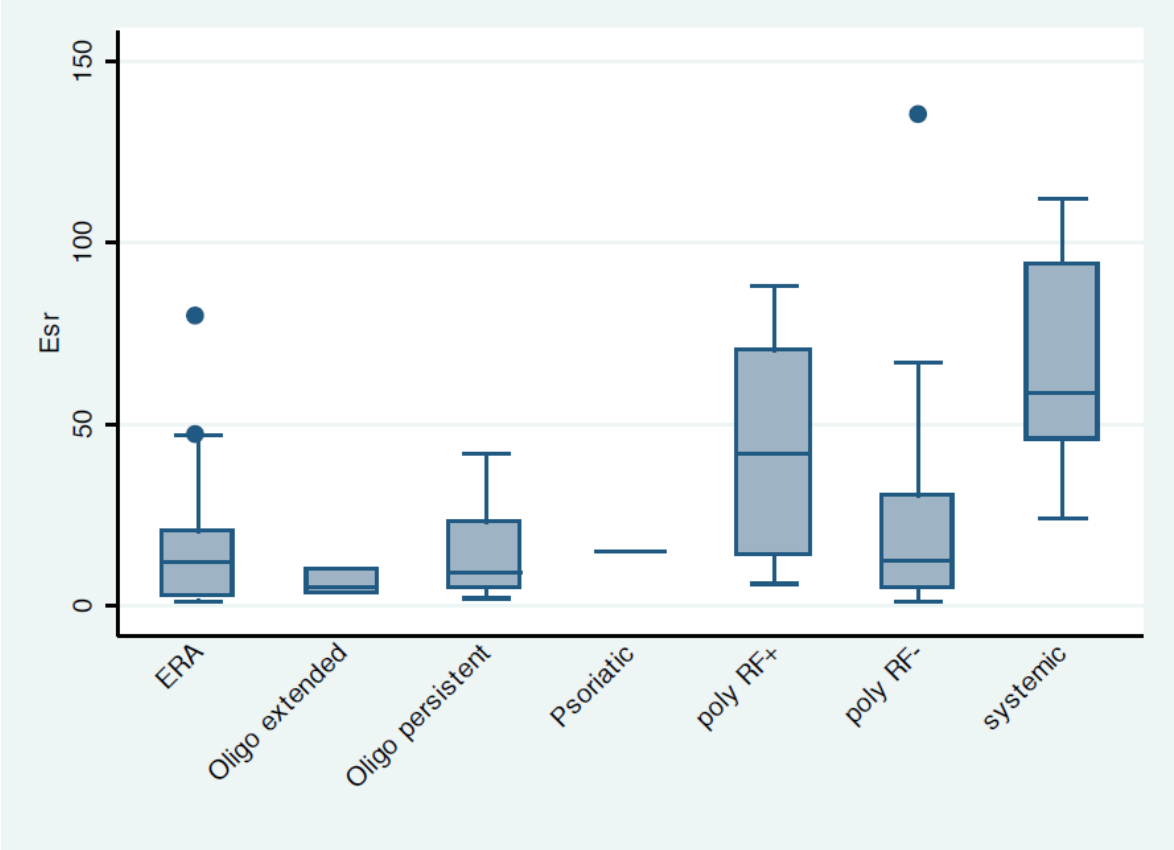

Figure 2

Active Joints vs Type

Active joints showed significant differences within type p=0.0013

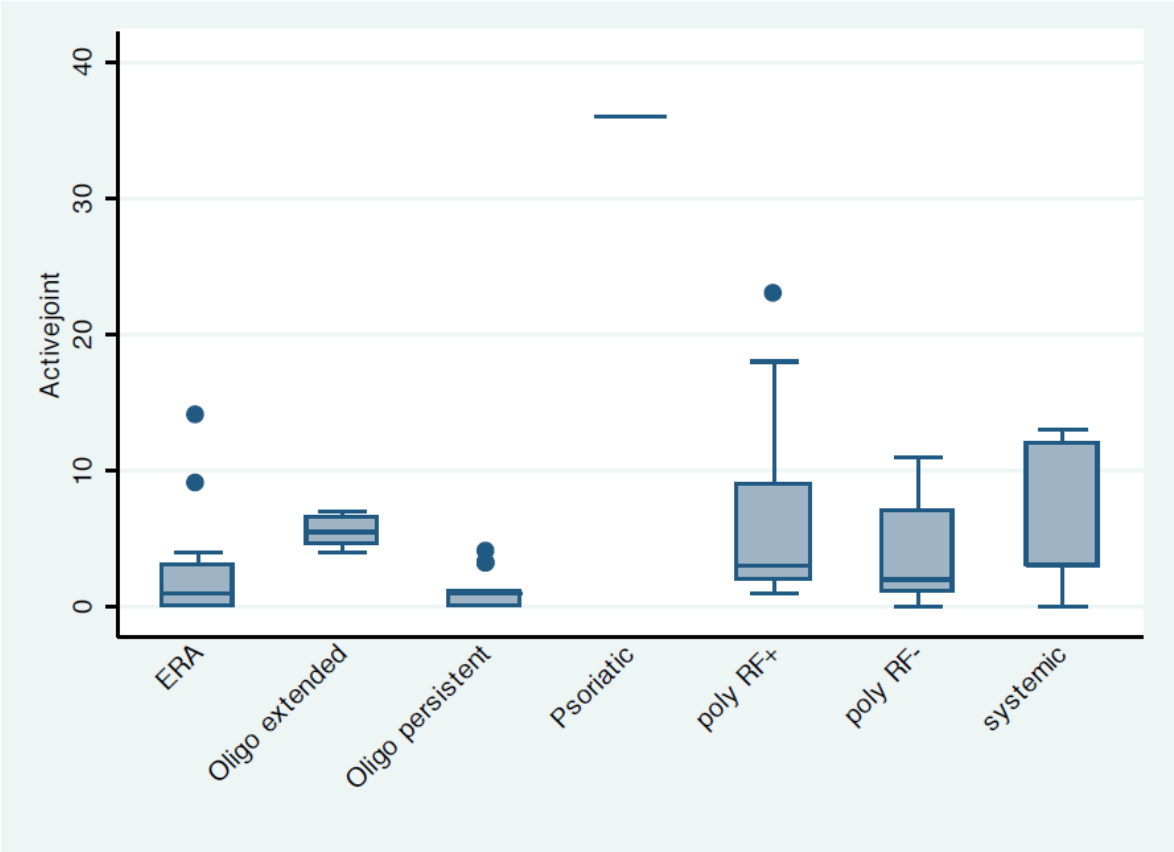

Figure 3

Limited Joints vs. Type

Limited Joint showed significant differences between subtype p=0.0003

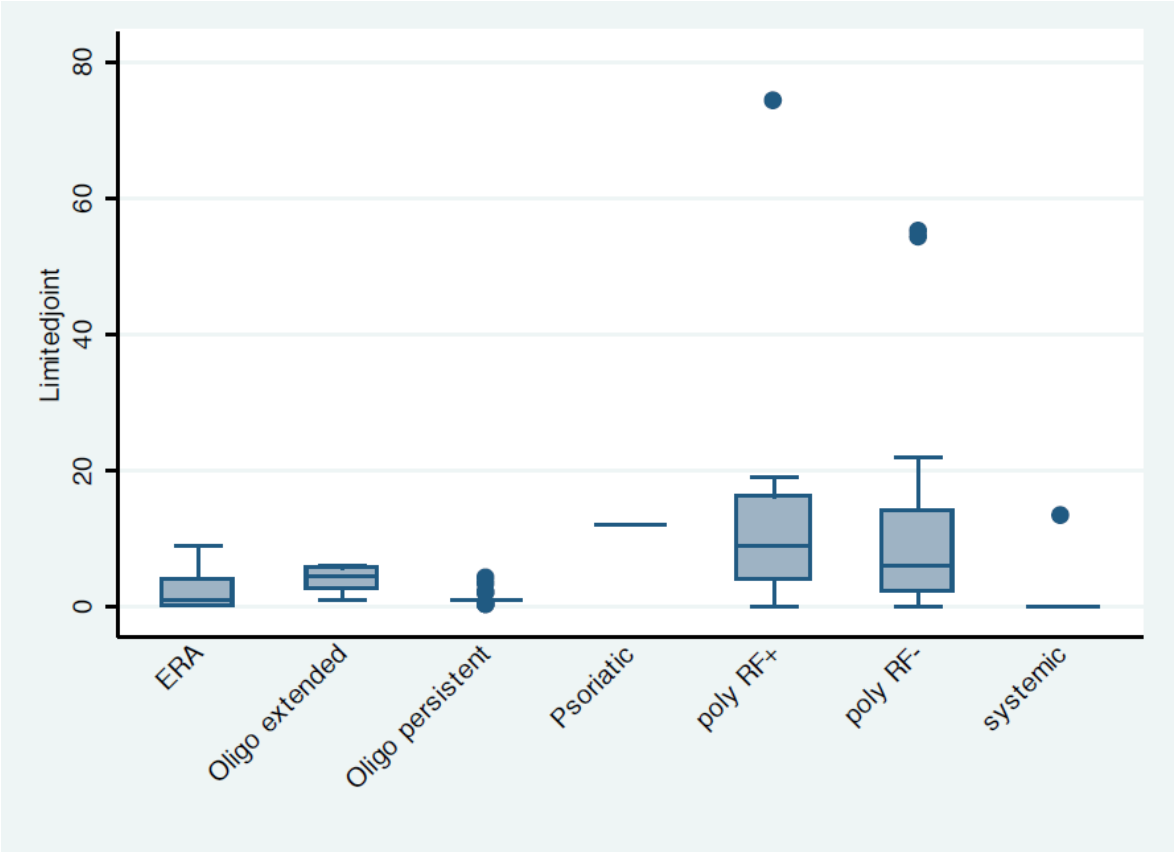

Figure 3

3 patients were ANA positive (1 oligoarthritis, 2 oligoextended).Of these 2 were immunofluorescent HEp 2 ANA assays and 1 was an ELISA. 18 were HLA B27 positive, all ERA patients. 11 patients were rheumatoid factor positive, all of whom had polyarthritis.

4.8 Discussion

JIA has a very different profile in the Western Cape of South Africa compared to other places where it has been described.

Table 3 summarises some of the differences between various populations in some recent studies that use the ILAR classification from developed and developing countries. The categorical variables are expressed as absolute frequencies and percentages. The numerical variables are all expressed as medians unless specified by *. Even though our data is not normally distributed the mean values are included in brackets for comparison purposes to the othe study cohorts. It must be noted that the studies were all done recruiting patients at random clinic visits, similiar to our data, except for the UK Childhood Arthritis Prospective Study (CAPS)[3], which recorded data from presentation and one year follow up.The one year data is included in the table below, but it is important to note as the outcome data (CHAQ, joints, VAS pain and general) are very different from the other cohorts.

All of the studies mentioned have been done in a tertiary hospital setting. This may skew results in 2 ways. Patients who attend a paediatric rheumatology clinic may have more severe disease than those in the community with milder disease. These milder forms have a higher likelihood of going into remission and may never make it to tertiary centres. Firstly, this may cause a skewed perception that JIA in an area is more severe than it may actually be.In addition, the subtypes causing the most severe disease will be most likely to attend a specialised clinic and therefore, skew the relative proportions of disease subtypes for that area.The various studies also had

differing methodology and this must therefore be noted as a potential limitation to the comparison below. The methodology of each study is summarised in table 4.

Table 3. *Median values represented unless * marks mean value.*

Study	Morocco[4]	UK[3]	Turkey[6]	Printo[2] W. Europe	Printo[2] E. Europe	Printo[2] Latin America	India[5]	South Africa
N	80	740	196	2102	668	397	235	78
Age current	10.85*		8.8*	9.4*	6.8*	10.7*		12.4*
Age at onset	7.53*	7.6	7.0*	5.4*	11.4*	6.6*	12	7.3*
Female	59%	64%	47%	83%	72%	68%	41.7%	50%
Systemic	26%	6%	15.3%	16.4%	23%	28.5%	8%	7.69%
Polyarthritis	31.5%	23%	37.2%	32%	33%	40.6%	29%	40.9%
Poly RF+		3%	6.6%				12%	14%
Poly RF-		20%	30.6%				17%	26.9%
Oligo Persistent	37,5%	48%	24.4%	29.5%	31.6%	21.9%	17%	21.8%
Oligo extended	5%	4%	9.6%	21.5%	12%	9%	4%	5%
ERA		7%	10.3%				36%	23%
Psoriatic		8%	1%				1%	1.28%
Undifferentiated		4%	2.5%				5%	
VAS pain(mm)	28.4*	9		28*	23*	27*		18(24.9*)
VAS general(mm)		6		25*	28*	24*		25(28.4*)
Limited joints	1.78*	0		5.9*	8.6*	10.1*		2(6.51*)
Active joints	4.39*	0		5.3*	6.7*	7.1*		2(3.85*)
CHAQ	0.84*	0.25		0.7*	0.6*	0.8*		0.5(0.73*)
ESR	28*	9		30.7*	27.7*	31.2*		14 (25.1*)

Table 4

Study	Setting	Method	No. Patients	Time period
Morocco[4]	Tertiary	Cross sectional prospective	80	18 months
UK[3]	Tertiary	Longitudional inception cohort	740	1 year
Turkey[6]	Tertiary	Retrospective record review	196	
PRINTO[2]	Tertiary	Multicentre case control cross sectional	3167	
India[5]	Tertiary	Longitudional cohort	235	11 years
South Africa	Tertiary	Prospective cross sectional	78	1 year

Age. Out of the above studies, the present data has the oldest mean current age(12.4 years) and the 2nd youngest mean age of onset (7.3 years). One of the reasons for this could be that the present studies' patients are being referred to treatment centres relatively long after their initial onset of symptoms.This cannot be confirmed as we did not capture the age of diagnosis versus the age of onset of symptoms, rather reported age at onset and current age at the time of the study. These are the same variables as the above studies, but we still have the oldest mean current age. In our socioeconomic scenario, we postulate that one of the most likely reasons for this is a delay in diagnosis, leading to a delay in inducing disease remission and therefore an older group of children who actively attend our clinics. The Western Cape is a large area that has many rural areas with difficult access. There is also a lack of awareness of JIA, delaying the time to diagnosis. JIA is often misdiagnosed as tuberculosis(TB). Often JIA is only considered after the child has not responded to 6 months of TB treatment or undergone synovial biopsies

to rule out TB. Although we collected the total number of patients who actually had TB, we did not collect the number who had been incorrectly diagnosed as TB and therefore had a diagnosis of JIA delayed. This would make an interesting study in the future. We theorise, therefore, that there is a longer disease course before presentation to a paediatric rheumatology centre.

*Sex.*Next to India[5](58.3%) and Turkey[6](53%), the present data has the 3rd highest rate of male JIA(50%), with all of the other regions having a female predominance as is classically described in western populations.There is a difference in sexual distribution per subtype. If ERA is excluded them from the our group, there is a 65% female predominance.

*Polyarthritis.*This data shows the highest rate of rheumatoid factor positive polyarthritis(14%) in the studies compared above, and the second highest rate of rheumatoid factor negative polyarthritis(26.9%) next to Turkey[6](30.6%). This is significant and in keeping with previous data that describes African population groups as having a higher risk of polyarthritic JIA [9;11;13]. A limitation that must be mentioned in the present study is that the ILAR criteria require at least 2 RF assays to be done at least 3 months apart in the first 6 months of the disease[1]. Due to constraints on resources, this is not standard practise in our clinics, and one positive or negative assay was considered sufficient to classify a patient with polyarthritis. This has been a difficulty with the ILAR classification, especially in poorly resourced settings, with it being mentioned in the Indian study[5] and in a previous study of Nordic children[14]. In the Nordic group 55% of children classified as polyarthritis could not be classified as RF positive or negative as the

RF had not been done twice[14]. It is postulated that this would probably cause RF positive patients to be underrepresented in our polyarticular subtype, as only one RF is being done, and that it may be more prevalent than is reported.

*Oligoarthritis.*Lower rates of oligoarthritis(21.8% oligopersistent, 5% oligoextended) are seen in the present cohort than described in Western populations. This is in keeping with previously described data that shows that non European populations have a decreased relative risk of suffering from oligoarthritis[9] . There is also a very low rate of ANA positivity described. A limitation that must be mentioned is that there are technical issues with the available laboratories, with only a small proportion of patients having had HEp2 immunofluorescent ANA studies done and the majority being ELISA studies. It has been shown that ELISA ANA testing shows fewer ANA than HEp 2 immunofluorescense testing[23;24].

Enthesitis related arthritis. The present data describes the second highest rate of ERA(23%), second only to the Indian[5] cohort(36%). It is much higher than the ERA rates in the data from the UK[3] (7%) and Turkey[6] (10.3%). The large PRINTO series states that there were too few ERA patients, so they were excluded from further consideration[2].This is an interesting finding as ERA has not been previously associated with an African population. It has been described as being more prevalent in Asian populations and Indian populations[9;5].

A postulated reason for this is the unique population mix that is prevalent in the Western Cape region of South Africa. The Western Cape has a different population to the rest of

South Africa, with a higher prevalence of coloured people (44%) compared to black (34.9%)[15] .This is not representative of the rest of the country where the majority of the population is black. The coloured population has mixed ancestry with some Asian and European heritage which may account for the high levels of ERA . It may also be due to a founder effect from the initial small population groups in the Cape. *Psoriatic.*There was also only 1 patient with psoriatic arthritis, which may be due to it being a rarer subgroup in our setting but often, a family history of psoriasis was difficult to elicit in our patients.

Functional disability and outcomes. The markers of functional disability(CHAQ), visual analogue scales for pain and general wellbeing, as well as biomarkers of disease (ESR) are compared to the other groups in the table below. Values are expressed as medians unless* marks mean. Even though our variables are not normally distributed, means are given in brackets for comparison purposes.

Table 5. *Values expressed as medians unless * marks mean*

	Morocco[4]	UK[3]	Printo[2] W Europe	Printo[2] E Europe	Printo[2] Latin America	South Africa
VAS pain(mm)	28.4*	9	25*	28*	24*	18(24.9*)
VAS general(mm)		6	28*	23*	27*	25(28.4*)
CHAQ	0.84*	0.25	0.7*	0.6*	0.8*	0.5(0.73*)
ESR	28*	9	30.7*	27.7*	31.2*	14 (25.1*)

This shows that our cohort has a comparable mean ESR, CHAQ, pain and general wellbeing, as the other groups except for the UK CAPS[3] study. As mentioned before, the

UK data is from a 1 year follow up and is therefore difficult for comparison purposes, but is a good example of excellent outcomes in a well resourced setting. A similiar longitudional study would be ideal in our patients to assess whether we are achieving comparable control of our patients' disease.

4.8 Conclusion

JIA in the Western Cape of South Africa has a very different profile to JIA that has been described elsewhere. There is an equal male to female predominance.Both RF positive and negative polyarthritis are more common than has been described elsewhere.There is a high a relatively high rate of joint limitation, functional disability, pain and poor general wellbeing in these polyarthritis patients. There is a higher rate of ERA than has been previously described in Africa. Lower rates of oligoarthritis are described. Disease presentation is often later than elsewhere due to socioeconomic factors, confounding diseases such as TB and lack of awareness and resources in paediatric rheumatology. There are difficulties with the ILAR classification in our setting, specifically regarding the requirement of 2 rheumatoid factor tests.

Therefore juvenile idiopathic arthritis has a unique disease profile and has unique challenges in the South African setting.

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5 Appendices

5.1 ILAR Classification

International League of Associations for Rheumatology Classification of Juvenile Idiopathic Arthritis: Second Revision, Edmonton, 2001

The primary aim of the International League of Associations for Rheumatology (ILAR) proposals for classification of juvenile idiopathic arthritis (JIA) is to delineate, for research purposes, relatively homogeneous, mutually exclusive categories of idiopathic childhood arthritis based on predominant clinical and laboratory features. As part of a continuing review process, the ILAR Taskforce on Classification of Childhood Arthritis met in Edmonton in 2001 to discuss modifications to the proposed JIA classification. Since the publication of the first revision of the original classification[1], a number of descriptive studies using the new classification have been reported[2–11]. The aims of this communication are 2 fold: to outline modifications to the revised classification proposed as a result of the Edmonton meeting, and to correct misconceptions highlighted by the published studies concerning the clinical use of the classification.

The Edmonton Revision

The changes embodied in the second revision of the classification are as follows:

1. Clarification of the definitions of each category.
2. Improvement in the congruity between inclusion and exclusion criteria.
3. Removal of the requirement that a dermatologist make the diagnosis of psoriasis.
4. Removal of the requirement that there be medical confirmation of HLA B27 associated disease in a relative.
5. Reduction in the age for criterion "3" of enthesitis related arthritis, and exclusion "b" from 8 years to 6 years of age.
6. Improvement in the consistency of the structure.

The impracticality of the requirement that a diagnosis of psoriasis be made by a dermatologist was recognized, and this requirement was modified so that the diagnosis of psoriasis could be made by a physician (not necessarily a dermatologist). Similarly, it is no longer required that there be medical confirmation of an HLA B27 associated disease in a relative to maintain inclusion "c." It is evident that it is very difficult to obtain a reliable history of psoriasis or an HLA-B27 associated disease in a second-degree relative. Therefore, a history of importance to the application of the criteria is restricted to the patient or a first degree relative (parents or siblings) only. The study of Murray, et al[5] indicated that the HLA B27 association is important in boys over the age of 6 years at onset of arthritis, and this age was substituted for 8 years in exclusion "b." Discrepancies between inclusion and exclusion criteria were resolved, and the exclusions were identified by the letters a, b, c, d, and e. Minor modifications in the definitions in the glossary have been made. It is hoped that these modifications will make the classification more transparent, consistent, and easy to apply. The descriptors suggested in the previous revision are unchanged. They do not form part of the classification as such, but many, such as the presence of antinuclear antibodies (ANA), may be important indicators of outcome, and are worthy of evaluation as possible modifiers of the current classification.

General Definition of JIA

Juvenile idiopathic arthritis is arthritis of unknown etiology that begins before the 16th birthday and persists for at least 6 weeks; other known conditions are excluded.

Exclusions

The principle of this classification is that all categories of JIA are mutually exclusive. This principle is reflected in the list of possible exclusions for each category:

a. Psoriasis or a history of psoriasis in the patient or first degree relative.

b. Arthritis in an HLA B27 positive male beginning after the 6th birthday.

c. Ankylosing spondylitis, enthesitis related arthritis, sacroiliitis with inflammatory bowel disease, Reiter's syndrome, or acute anterior uveitis, or a history of one of these disorders in a first degree relative.

d. The presence of IgM rheumatoid factor on at least 2 occasions at least 3 months apart.

e. The presence of systemic JIA in the patient.

The application of exclusions is indicated under each category, and may change as new data become available.

Categories

Systemic Arthritis

Definition: Arthritis in one or more joints with or preceded by fever of at least 2 weeks' duration that is documented to be daily ("quotidian") for at least 3 days, and accompanied by one or more of the following:

1. Evanescent (nonfixed) erythematous rash
2. Generalized lymph node enlargement
3. Hepatomegaly and/or splenomegaly
4. Serositis

Exclusions: a, b, c, d.

Oligoarthritis

Definition: Arthritis affecting one to 4 joints during the first 6 months of disease. Two subcategories are recognized:

1. Persistent oligoarthritis: Affecting not more than 4 joints throughout the disease course
2. Extended oligoarthritis: Affecting a total of more than 4 joints after the first 6 months of disease
Exclusions: a, b, c, d, e.

Polyarthritis (Rheumatoid Factor Negative)
Definition: Arthritis affecting 5 or more joints during the first 6 months of disease; a test for RF is negative.
Exclusions: a, b, c, d, e.

Polyarthritis (Rheumatoid Factor Positive)
Definition: Arthritis affecting 5 or more joints during the first 6 months of disease; 2 or more tests for RF at least 3 months apart during the first 6 months of disease are positive.
Exclusions: a, b, c, e.

Psoriatic Arthritis
Definition: Arthritis and psoriasis, or arthritis and at least 2 of the following:
1. Dactylitis
2. Nail pitting or onycholysis
3. Psoriasis in a first degree relative
Exclusions: b, c, d, e.

Enthesitis Related Arthritis
Definition: Arthritis and enthesitis, or arthritis or enthesitis with at least 2 of the following:
1. The presence of or a history of sacroiliac joint tenderness and/or inflammatory lumbosacral pain
2. The presence of HLA B27 antigen
3. Onset of arthritis in a male over 6 years of age
4. Acute (symptomatic) anterior uveitis
5. History of ankylosing spondylitis, enthesitis related arthritis, sacroiliitis with inflammatory bowel disease, Reiter's syndrome, or acute anterior uveitis in a first-degree relative
Exclusions: a, d, e.

Undifferentiated Arthritis
Definition: Arthritis that fulfills criteria in no category or in 2 or more of the above categories.

Descriptors
A number of "descriptors" have been proposed to gather further information on the patterns of the clinical picture. These include age at onset, further description of the arthritis (large joints, small joints, symmetry, upper or lower limb predominance, and individual joint involvement), disease course (number of joints), presence of ANA, chronic or acute anterior uveitis, and the HLA allelic associations. The potential value of ANA as a diagnostic criterion has received a great deal of attention, but there is insufficient evidence to support its inclusion at this time. The descriptors are not part of the classification of JIA, but new data about them may allow reclassification in the future.

Definitions of Terms
Arthritis: Swelling within a joint, or limitation in the range of joint movement with joint pain or tenderness, which persists for at least 6 weeks, is observed by a physician, and is not due to primarily mechanical disorders or to other identifiable causes.
Dactylitis: Swelling of one or more digits, usually in an asymmetric distribution, which extends beyond the joint margin.
Enthesitis: Tenderness at the insertion of a tendon, ligament, joint capsule, or fascia to bone.
Inflammatory lumbosacral pain: Lumbosacral spinal pain at rest with morning stiffness that improves on movement.
Nail pitting: A minimum of 2 pits on one or more nails at any time.
Number of affected joints: Joints that can be individually evaluated clinically are counted as separate joints.
Positive test for rheumatoid factor (RF): At least 2 positive results (as routinely defined in an accredited laboratory), at least 3 months apart, during the first 6 months of disease.
Psoriasis: As diagnosed by a physician (but not necessarily a dermatologist).
Quotidian fever: Fever that rises to ≥ 39°C once a day and returns to ≤ 37°C between fever peaks.
Serositis: Pericarditis and/or pleuritis and/or peritonitis.
Sacroiliac joint arthritis: Presence of tenderness on direct compression over the sacroiliac joints.
Spondyloarthropathy: Inflammation of entheses and joints of the lumbosacral spine.
Uveitis: Chronic anterior uveitis as diagnosed by an ophthalmologist.

Use of the Classification in the Published Literature
The ILAR classification requires validation before it is used routinely in the clinical setting. To some extent this process has been advanced by studies already published[2-18], but further challenges remain including evaluation of the requirement of repeated testing of rheumatoid factor, and the development of precisely defined categories that would include all children with chronic inflammatory arthritis of unknown cause.

It is essential that the ILAR classification be used with accuracy. A number of publications appear to have simply substituted the letters JIA for JRA (juvenile rheumatoid arthritis) or JCA (juvenile chronic arthritis), without due attention to the details of inclusion and exclusion criteria. The ILAR criteria represent not only a change in terminology, but in definition. It is important that deviations from

the published criteria are clearly noted, lest they result in inability to interpret and compare the reported data. It is a requirement, for example, for classification in the polyarthritis rheumatoid positive category, that RF be present on 2 occasions at least 3 months apart. This was intended to make certain the unrelated RF positivity, such as that which might follow an infection, not be allowed to obscure what was felt to be significant persistent RF test positivity. This may be contrary to usual clinical practice, and has therefore been an impediment to the easy application of the criteria. Although RF testing would be ideally performed during the first 6 months of disease, this may not always be possible, and test results obtained at a later time should then be used. These requirements should be evaluated; the results of such an evaluation may well influence the criteria. The ILAR committee has concluded that until such data are forthcoming, in keeping with the principles adopted by the committee, the requirement for 2 positive tests for RF will be retained in the present revision.

It is anticipated that the proposed classification will undergo further revision in order to correct anomalies, and in response to new information. Such changes would be incorporated if they resulted in a demonstrable and objective improvement in homogeneity of the categories in the classification. The ILAR classification has proved useful in sparking controversy, questions and international debate, and research about JIA. The prospective gathering of new clinical information has been stimulated and will lead to an improved understanding of these diseases.

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5.2 CHAQ English

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

We are interested in learning how your child's illness affects his/her ability to function in daily life. Please feel free to add any comments on the back of this page. In the following questions, please tick the one response which best describes his/her usual activities OVER THE PAST WEEK. ONLY NOTE THOSE DIFFICULTIES OR LIMITATIONS WHICH ARE DUE TO ILLNESS. If most children at your child's age are not expected to do a certain activity, please mark it as 'not applicable' For example, if your child has difficulty in doing a certain activity or is unable to do it because he/she is too young, but not because he/she is RESTRICTED BY ILLNESS, please mark it as 'not applicable'.

	Without ANY Difficulty	With SOME difficulty	With MUCH difficulty	UNABLE to do	Not applicable
DRESSING & PERSONAL CARE					
Is your child able to:					
- Dress, including tying shoelaces and doing buttons?	☐	☐	☐	☐	☐
- Shampoo his/her hair?	☐	☐	☐	☐	☐
- Remove socks?	☐	☐	☐	☐	☐
- Cut fingernails?	☐	☐	☐	☐	☐
GETTING UP					
Is your child able to:					
- stand up from a low chair or floor?	☐	☐	☐	☐	☐
- Get in and out of bed ?	☐	☐	☐	☐	☐
EATING					
Is your child able to:					
- Cut his/her own meat?	☐	☐	☐	☐	☐
- Lift a cup or glass to mouth?	☐	☐	☐	☐	☐
- Open a new unseal box?	☐	☐	☐	☐	☐
WALKING					
Is your child able to					
- Walk outside on flat ground?	☐	☐	☐	☐	☐
- Climb up five steps?	☐	☐	☐	☐	☐

*** Please tick any AIDS or DEVICES that your child usually uses for any of the above activities:**

Devices used for dressing (button hook, zip pull, long-handled shoe horn, etc.)	☐		
Walking stick	☐		
Walking frame	☐	Built up pencil or special utensils	☐
Crutches	☐	Special or built up chair	☐
Wheelchair	☐	Other _____	☐

*** Please tick any categories for which your child usually needs help from another person BECAUSE OF PAIN OR ILLNESS:**

Dressing and personal care	☐	Eating	☐
Getting up	☐	Walking	☐

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	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE To do	Not Applicable
HYGIENE					
Is your child able to					
- Wash and dry your entire body?	☐	☐	☐	☐	☐
- Take a bath (get in and get out)?	☐	☐	☐	☐	☐
- Get on and off the toilet or potty?	☐	☐	☐	☐	☐
- Brush teeth?	☐	☐	☐	☐	☐
- Comb/brush hair?	☐	☐	☐	☐	☐
REACH					
Is your child able to:					
- Reach and get down a heavy object such as a large game or books from just above his/her head?	☐	☐	☐	☐	☐
- Bend down to pick up clothing or a piece of paper from the floor?	☐	☐	☐	☐	☐
- Pull on a jumper over his/her head?	☐	☐	☐	☐	☐
- Turn neck to look back over shoulder?	☐	☐	☐	☐	☐
GRIP					
Is your child able to:					
- Write or scribble with pen or pencil?	☐	☐	☐	☐	☐
- Open car doors?	☐	☐	☐	☐	☐
- Open jars, which have been previously opened?	☐	☐	☐	☐	☐
Turn taps on and off?	☐	☐	☐	☐	☐
- Push open a door when you have to turn a door knob?	☐	☐	☐	☐	☐
ACTIVITIES					
Is your child able to:					
- Run errands and shop?	☐	☐	☐	☐	☐
- Get in and out of a car, toy car or school bus?	☐	☐	☐	☐	☐
- Ride bike or tricycle?	☐	☐	☐	☐	☐
- Do household chores (eg. Wash dishes, take out rubbish, hovering)	☐	☐	☐	☐	☐
- Run?	☐	☐	☐	☐	☐

*** Please tick any AIDS or DEVICES that your child usually uses for any of the above activities:**

Raised toilet seat	☐	Bath rail	☐
Bath seat	☐	Long-handled appliances for reach	☐
Jar opener (for jars previously opened)	☐	Long-handled appliances in bathroom	☐

*** Please tick any categories for which your child usually needs help from another person BECAUSE OF ILLNESS:**

Hygiene	☐	Gripping and opening things	☐
Reach	☐	Errands and chores	☐

PAIN : We are also interested in learning whether or not your child has been affected by pain because of his or her illness. How much pain do you think your child has had IN THE PAST WEEK? Place a mark on the line below, to indicate the severity of the pain

No pain 0 ——————————— 100 Very severe pain

GENERAL EVALUATION: Considering all the ways that arthritis affects your child, rate how he/she is doing overall by placing a single mark on the line below.

Very well 0 ——————————— 100 Very poor

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5.3 CHAQ Xhosa

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

IPHEPHA LEMIBUZO ENGOKUHLOLWA KWEMPILO YOBUNTWANA (CHAQ)

Kwesi candela sinomlla wokufunda ukuba iingalo nomtwana wakho sinahphazela njani ekwenzeni imisebenzi yemihla-ngemihla. Ungangeza ngokukhuthalelekileyo naziphi na iindawo ofuna ukuzongeza ngokuzibhala emva kule fomu. Kule mibuzo ilandelayo, nonda ukhangele nyikhaza ngomso indlela umtwana wakho enza ngayo izinto ngokweseiphelo(i-seteji yonke lonke) KULE VEKI IPHELAYO QAPHELA IINZIMA OKANYE IZITHINTELO EZIBANGELWA KUKUGULA KUPHELA. Ukuba ngaba unizi lwabantwana abantanga- nye kunye nako mntwana wakho abalindelekanga ukuba benze iinsety enzana ethile, nonda uphawule ngo- "Ayikuphazeleki." Umzekelo, ukuba ngaba umtwana wakho unobunzima ekwenzeni imisety enzana ethile okanye akalwazi ukuyenza kuba esemncinci kodwa HAYI kuba ETHINTELWE KUKUGULA, nonda uyiphawule ngo-"Ayikuphazeleki."

	Ngephandle Kobunzima	Nobunzima obuncinci	Nobunzima obuthe chethe	Akalwenzi-ukuyenza	Asikuphazeleki
UkuNxiba nokuziQoqosha					
Umtwana wakhony akwazi uku					
- Zinxibisa, kuqoka nokubopha imity a yezihlanga nokuziphobotha?	□	□	□	□	□
- Hlambaimiweir zakhe?	□	□	□	□	□
- zikhuhla ikawusi?	□	□	□	□	□
- zidubha inziplo?	□	□	□	□	□
Ukuphakama					
Umtwana wakhony akwazi uku					
- Phakama kwisitulowisentsini okanyenegangathwini?	□	□	□	□	□
- Khwela nokuzehlela ebhedini okanye kwibhenli yemtwana?	□	□	□	□	□
Ukutya					
Umtwana wakho uyakwazi uku:					
- Zivikela nyamayakhe?	□	□	□	□	□
- Phakamisa igilasiokanye ikomityi yakhe ayizise emlonyeni?	□	□	□	□	□
- Vula ibhokisi entsha yesityeli?	□	□	□	□	□
Ukuhamba					
Umtwana wakhony akwazi uku					
- hamba ngaphandlebalesi elisicaba?	□	□	□	□	□
- nyuka kangangeenyawo ezintlanu kumangwaqwa?	□	□	□	□	□

* Nonda ujonge naliphi na UNCEDO okanye IZIXHOBO umtwan wakho aphele ukuzisebenzisa kuyo nayiphi na kule misebenzi ingentla:

Intonga yokuhamba	□	Izixhobo ezisetyenziswa ekunxibeni (ibhuku yephosha, isivali setipha,umzuphe wokunxiba izihlangu emphambo mde, njl-njl.)	□
Izixhobo zokuhamba	□	Ipensile elungiselelweyo okanye izixhobo ezizodwa	□
Intonga zokuhamba	□	Izitulo ezisodwa okanye emilungiselelweyo	□
situlo esinamavili	□	Okunye Cacisa: ----------	□

* Nonda ujonge naziphi na izigaba apho umtwana wakho aphele ukufuna kuzo usondo lomnye umntu NGENXA YOKUGULA:

Ukunxiba nokuziQoqosha	□	Ukutya	□
Ukuphakama	□	Ukuhamba	□

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

	Ngaphandle Kobunzima	Nobunzi ima obuncinci	Nobunzima obuthe chatha	Akakwazi-ukuyenza	Akuchaphazeleki
Ukunxiba					
Umntwana wakho uyakwazi uku:					
- Zihlambe azonxibe uzinxibe wonke?	☐	☐	☐	☐	☐
- Tshatha iintsapho okuphuthelwayo (ezingenile uziphuhlisile kunoi)?	☐	☐	☐	☐	☐
- Zikhwelela azehlele kwisihlalo segumbi langasese okanye epowisini yakhe?	☐	☐	☐	☐	☐
- zihlambe amazinyo?	☐	☐	☐	☐	☐
- zikama/ukuzibrasha iinwele?	☐	☐	☐	☐	☐
Ukufikelela					
Umntwana wakho uyakwazi uku:					
- Fikelela othule into enzima Njengomdlalo omkhulu okanye iincwadi ezingentla kwentloko yakhe?	☐	☐	☐	☐	☐
- Goba athole iimpahla okanye iphetshana elisemgangathweni?	☐	☐	☐	☐	☐
- qabelisa impahla enabujezisha Entlokweni yakhe?	☐	☐	☐	☐	☐
- jika intamo ajonge ngaphaya kwegxalaba lakhe?	☐	☐	☐	☐	☐
Ukubamba nkqi					
Umntwana wakho uyakwazi uku:					
- Bhala okanye enhoqoze ngapen okanye ipensile?	☐	☐	☐	☐	☐
- Vula iingcango zemoto?	☐	☐	☐	☐	☐
- Vvula iijars ebezivulwe ngaphambili?	☐	☐	☐	☐	☐
- vula avale iitepu?	☐	☐	☐	☐	☐
- tybala ucango na ezakulijija	☐	☐	☐	☐	☐
Ukuthunywa, imisetyenzana nokudlala					
Umntwana wakho uyakwazi uku:					
- Thunywa nokuya kuthenga?	☐	☐	☐	☐	☐
- Zingenele nokuziphumela emotweni okanye kwimoto yokudlala okanye ebhasini yesikolo?	☐	☐	☐	☐	☐
- khwela ibhayisekile okanye itrayisekili?	☐	☐	☐	☐	☐
- kwenza imisetyenzana yasekhaya ajonze. Ukuhlamba izitya, ukukhupha inkunkuma, ukucoca umgangatho, ukucoca iyadi, ukondla, ukucoca igumbi)?	☐	☐	☐	☐	☐
- baleka nokudlala?	☐	☐	☐	☐	☐

*** Nceda ujonge nakuphi na UNCEDO okanye IZIXHOBO umntwana wakho aqhele ukuzisebenzisa kuyo nayiphi na kule misebenzi ingentla:**

Isihlalo segumbi langasese esiny uswayo	☐	Isivuli sejar(kwezo bezivulwe ngaphambili)	☐
Isihlalo esisetyenziswa sokuhlambela	☐	Izixhobo ezisisiphambo mde ukwenza ukufikelela ngoeso	☐
Intsimbi yesitya sokuhlambela	☐	Izixhobo ezisisiphambo mde kwigumbi lokuhlamba	☐

*** Nceda ujonge nayiphi na iziqaba apho umntwana wakho aqhele ukufuna luncedo komnye umntu NGENXA YOKUGULA:**

Ukunxiba	☐	Ukubamba nkqi nokuvula izinto	☐
Ukufikelela	☐	Ukuthunywa, imisetyenzana nokudlala	☐

Sikwanomdla wokwazi ukuba ingaba umntwana wakho ngenxa yokugula kwakhe, ukhe wafunyanwa zintlungu na okanye hayi. Ucinga ukuba umntwana wakho ufunyenwe kangakanani na zintlungu KULE VEKI IPHELILEYO?

Beka uphawu lwakho kulo mgca ungezantsi ukubonakalisa ubunzulu beentlungu.

Akukho Zintlungu 0 |--| 100 Kubuhlungu Kakhulu

UPHONONONGO LWEHLABATHI: Ekuqwalaseleni zonke iindlela umntwana wakho achatshazelwa ngayo sisifo samathambo, thelekelela ukuba uphila njani ngokubeka uphawu kulo mgca ungezantsi.

Kakuhle kakhulu 0 |--| 100 Kakubi kakhulu

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5.4 CHAQ Zulu

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

Iphepha Lemibuzo Lokuhlola Izinto Sempilo Yobungane nelaziwe ngokuthi yi-CHAQ ngamafuphi.

Kulesi sigaba sifisa ukwazi ukuthi ngabe ukugula kwengane y akho kukuphazamisa kanjani ukukwazi ukuzehenza kwayo nsuku zonke zempilo yayo. Sicela ukhulukhe ukwenzeta noma y ikuphi ukuphawula ngemuva kokona lehi khasi. Kufe mibuzo elandelayo, sicela ukuthi ubheke impendulo okuy iyona echaza kangcono imisebenzi ejwayele ukwenziwa yingane y akho (ukungenani ngaphezu kosuku lonke) KODWA-KE KULELI SONTO ELEDLULE KUPHELA. SICELA UBHALE LOBO BUNZIMA NOMA IMIKHAWULO INGANE YAKHO ENAYO NGENXA YESIFO ESITHILE LESO. Uma izingane ezinging ezikule minyaka okuyo ingane ayikho zingalindelekile ukuthi zenze leyo misebenzi, sicela ufake umaki othi "Lokhu Akungeni". Isiboneki, uma ingane y akho ikuthola kunzima ukwenza umsebenzi othile noma ingakwazi ukwenza kokho ngoba incane kakhulu ukuthi ingakwenza kodwa lihay i ngoba INQUNDWA OKANYE IVINUWA YISIFO UKUTHI IKWENZE, lapho-ke sicela ufake umaki othi "Lokhu Akungeni."

	Ngokwedlu KOBUN-ZIMA	Nzobunzima OBUNGA-THEN	Nzobunzima OBUKHULU	Akukwenzi UKUK-WENZA	Lokhu AKUNGENI
Ukuqgoka nokuzilungiza					
Ngabe ingane y akho iy akwazi yini:					
- Ukuqgoka, ukufaka nokubopha izisathulo kanye nokufaka izinkinobho?	☐	☐	☐	☐	☐
- ukugeza izinwele zayo?	☐	☐	☐	☐	☐
- ukukhumula amasokisi?	☐	☐	☐	☐	☐
- ukunquma izinzipho?	☐	☐	☐	☐	☐
Ukuvuka					
Ngabe ingane y akho iy akwazi yini:					
- ukuvukuma esihlalweni Esifushane noma kwiphansi lendlu?	☐	☐	☐	☐	☐
- Ukuqbela nokwehla esibhedeni noma ukuvuka esibhedeni ephakeme wezingane?	☐	☐	☐	☐	☐
Ukudla					
Ngabe ingane y akho iy akwazi yini:					
- ukuziselela iny ama?	☐	☐	☐	☐	☐
- ukuphakamisa inkomishi noma ingilazi iy e emlonyeni ?	☐	☐	☐	☐	☐
- ukuvula ibhokisi elisha lamasiy eli?	☐	☐	☐	☐	☐
Ukuhamba					
Ngabe ingane y akho iy akwazi yini:					
- ukuhamba endaweni evulekile futhi ey isicaba ngaphandle?	☐	☐	☐	☐	☐
- ukuqbela izitebhisi eziy isikhaxu?	☐	☐	☐	☐	☐

*** Sicela ukheke IZINSIZA noma IZINTO esizosa ukuzisebenzisa yingane yakho kunoma yimiphi le misebenzi echiwe ngenhla:**

Isduku Yokudondoluzela	☐	Izinto ezisetshenziselwa ukugqoka(okokulenza izinkinobho, okokulenza izipho, okokufika izisathulo okunesibambo eside)	☐
Okokuhamba (i-walker)	☐	Umuzi oy isipenduli wokuhlala ubuthwana ubuto-ZRA	☐
Izindlela zokuhamba ezinsili	☐	Isihlalo esiy isipendueli noma esiphakeme	☐
Isihlalo samasondo	☐	Okunye (kusho ngqamu): _____	☐

*** Sicela ukheke noma yimiphi imikhakha lapho khona ingane yakho izwisiza ukudinga usizo oluvela kumuntu umunye kuyena NGENXA YESIFO ESIVIPHETHE:**

Ukuqgoka nokuzilungiza	☐	Ukudla	☐
Ukuvuka	☐	Ukuhamba	☐

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

	Ngaphandle KOBUNZIMA	Ngobunzima OBUNGATHEN	Ngobunzima OBUKHULU	Akakwazi UKUKWENZA	Lokhu AKUNGENI
Ukuhlanzeka					
Ngabe ingane yakho iyakwazi yini:					
- ukugeza yonke umzimba wonke?	☐	☐	☐	☐	☐
- ukugezela endishini (ingene iphinde iphume endishini)?	☐	☐	☐	☐	☐
- ukuhlala nokwehlika Kwisihlalo sendlu yangasese noma kwisihlalo sesigezsi?	☐	☐	☐	☐	☐
- ukuxubha amazinyo ayo?	☐	☐	☐	☐	☐
- ukukama/ukubhulasha izinwele?	☐	☐	☐	☐	☐
Ukufinyelela					
Ngabe ingane yakho iyakwazi yini:					
- ukufinyelela futhi ithathe into esindayo iyibeke phansi njengegeme eliculu noma izincwadi ezibekwe endaweni engaphezu kwekhanda layo?	☐	☐	☐	☐	☐
- ukugoba ithathe izimpahla noma isicucu sephepha kwiphansi lendlu?	☐	☐	☐	☐	☐
- ukugqoka into egqokwa ngokufakwa ekhanda kuqala?	☐	☐	☐	☐	☐
- ukuphendula intamo ukubheka ngemuva kwehlombe layo?	☐	☐	☐	☐	☐
Ukubamba					
Ngabe ingane yakho iyakwazi yini:					
- ukubhala noma ukukhwebha ngepeni?	☐	☐	☐	☐	☐
- ukuvula iminyango yemoto?	☐	☐	☐	☐	☐
- ukuvula izivalo ezisontwayo ebese zivele zivuliwe?	☐	☐	☐	☐	☐
- ukuvula nokuvala izinto ezijikiswayo?	☐	☐	☐	☐	☐
- ukuphusha iminyango uma kufanele ajikise isibambo kuwo?	☐	☐	☐	☐	☐
Ukwenza Izinto Ezincane Ezingatheni, Imisetshenzana, kanye Nokudlala					
Ngabe ingane yakho iyakwazi yini:					
- ukwenza izintyo ezincane Ezingatheni kanye nokuya esitolo?	☐	☐	☐	☐	☐
- ukungena nokuphuma emotweni, etho-yizisi lemoto noma kwibhasi lesikole?	☐	☐	☐	☐	☐
- ukugibela ibhayisikili noma ibhayisikilana elinamasondo amathathu?	☐	☐	☐	☐	☐
- ukwenza imisebenzi emjengokugeza izitsha, ukuchitha udoti, ukuvakhuyuma, ukusebenza egadeni, ukwendlala/ukwendlala umbhede, ukuhlanza indlu)?	☐	☐	☐	☐	☐
- ukugijima nokudlala?	☐	☐	☐	☐	☐

- **Sicela ukheke IZINSIZA noma IZINTO ezivame ukusetshenziswa yingane yakho kunoma yimiphi le misebenzi echiwo ngenhla:**

Isihlalo sendlu yangasese esiphakanyisiwe	☐	Okokuvula Izivalo (mazikuzavulwa phambilini)	☐
Isihlalo sendishi yokugezela	☐	Izinto ezinezibambo ezinde ukuze ifinyelele kuzo	☐
Insimbi yendishi yokugezela	☐	Izinto ezinezibambo ezinde endlini yokugezela	☐

*** Sicela ukheke noma yimiphi imikhakha lapho khona ingane yakho ivamise ukudinga usizo oluvela komunye umuntu kuyona NGENXA YESIFO ESIYIPHETHE:**

Inhlanzeko	☐	Ukubamba kanye Nokuvula izinto ezithile	☐
Ukufinyelela	☐	Ukwenza Izinto Ezincane Ezingatheni, Imisetshenzana, kanye Nokudlala	☐

Singathanda futhi ukwazi ukuthi ngabe ziikhona yini izinhlungu ezibambe ingane yakho ngenxa yalesi sifo sayo. Ngabe ngokucabanga kwakho, bungakanani ubuhlungu obuzwiwe yingane yakho ngenxa yalesi sifo esiphethe KULELI SONTO ELEDLULE NA?
Sicela wenze umaki kulo mudwa ongezansi ukukhombisa ubukhulu bobuhlungu bengane yakho.

Akukho Buhlungu 0 |--| 100 Kubuhlungu
Ukuzuka Lapha   Kakhulu Lapha

UKULINGANISA OKUPHELELE: Uma ukheka zonke izindlela isifo esimajoyinti esimiimba esikhasela ngayo ingane yakho, sicela usho ukuthi ngabe ingane yakho iphila kahle kangakanani ngalesi sifo ngokuthi wenze umaki kulo mudwa ongezansi.

Kahle kakhulu 0 |--| 100 Kabi kakhulu

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5.5 CHAQ Afrikaans

CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

VRAELYS: KINDERGESONDHEID

In hierdie afdeling wil ons graag uitvind hoe jou kind se siekte sy/haar vermoë beinvloed om daaglikse take te verrig. As jy wil kan jy bykomende inligting of kommentaar op die agterkant van hierdie vorm verstrek. Merk asb. die antwoord op elk van die volgende vrae wat jou kind se gewone gedrag OOR DIE AFGELOPE WEEK die beste omskryf. MERK NET DIE PROBLEME OF BEPERKINGS WAT DEUR DIE SIEKTE VEROORSAAK IS. Indien 'n sekere bedrywigheid nie normaalweg van kinders van jou kind se ouderdom verwag word nie, maak asb. jou merk in die kolom "Nie van toepassing nie". Met ander woorde, as jou kind sukkel met 'n sekere taak omdat by/sy te jonk is, en NIE omdat by/sy DEUR DIE SIEKTE VERHINDER WORD NIE, merk asb. die antwoord "Nie van toepassing nie".

Slegs weens JIA-siekte

	Sukkel glad nie	Sukkel bietjie	Sukkel baie	Kan dit nie doen nie	Nie van toepassing nie
Kleredrag en Netheid					
Kan jou kind:					
- Aantrek, ook skoenveters en knope vasmaak?	☐	☐	☐	☐	☐
- Sy/haar hare was?	☐	☐	☐	☐	☐
- Sokkies uittrek?	☐	☐	☐	☐	☐
- Vingernaels sny?	☐	☐	☐	☐	☐
Opstaan					
Kan jou kind:					
- Van die vloer of van 'n lae stoel opstaan?	☐	☐	☐	☐	☐
- In of uit die bed klim of regop staan in 'n kinderbed?	☐	☐	☐	☐	☐
Eet					
Kan jou kind					
- self sy / haar vleis sny?	☐	☐	☐	☐	☐
- 'n koppie of glas na sy/ haar mond bring?	☐	☐	☐	☐	☐
- 'n nuwe pakkie ontbytkos oopmaak?	☐	☐	☐	☐	☐
Stap					
Kan jou kind					
- In die buitelug op gelyk grond stap?	☐	☐	☐	☐	☐
- vyf trappies opstap?	☐	☐	☐	☐	☐

*** Merk asb. enige HULPMIDDELE of TOESTELLE wat jou kind gewoonlik gebruik om hom/haar te help met enige van die bogenoemde bedrywighede:**

Stapstok	☐	Toestel om te help aantrek (knoophaak, ritssluiter-trekker, skoenlepel met lang handvatsel ens.)	☐
Staptoestel	☐	Aangepaste potlood of ander spesiale instrument	☐
Krukke	☐	Spesiale of aangepaste stoel	☐
Rolstoel	☐	Ander (gee besonderhede): _____	☐

*** Merk asb. met watter klas bedrywighede jou kind gewoonlik hulp nodig het WEENS DIE SIEKTE:**

Aantrek en netheid	☐	Eet	☐
Opstaan	☐	Stap	☐

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CHILDHOOD HEALTH ASSESSMENT QUESTIONNAIRE

	Sukkel glad nie	Sukkel bietjie	Sukkel baie	Kan dit nie doen nie	Nie van toepassing nie
Higiëne					
Kan jou kind					
- sy/haar hele liggaam was en afdroog?	☐	☐	☐	☐	☐
- bad (en ook in- en uitklim)?	☐	☐	☐	☐	☐
- toilet of kamer-potstoel gebruik (op- en afklim)?	☐	☐	☐	☐	☐
- syhaar tande borsel?	☐	☐	☐	☐	☐
- syl haar hare kam of borsel?	☐	☐	☐	☐	☐
Bykom					
Kan jou kind					
- 'n swaar voorwerp soos swaar speelgoed of boeke raakvat en aftel van 'n rak net bokant syhaar kop?	☐	☐	☐	☐	☐
- afbuk en klerasie of 'n stuk papier van die vloer af optel?	☐	☐	☐	☐	☐
- 'n trui oor syhaar kop trek?	☐	☐	☐	☐	☐
- syhaar nek draai om oor syhaar skouer te kyk?	☐	☐	☐	☐	☐
Vasvat / vashou					
Kan jou kind					
- met 'n pen of potlood skryf of krap?	☐	☐	☐	☐	☐
- motordeure oopmaak?	☐	☐	☐	☐	☐
- flesse oopmaak wat al voorheen oop-gemaak is ?	☐	☐	☐	☐	☐
- krane oop- en toedraai?	☐	☐	☐	☐	☐
- 'n deur oopmaak as hy/ sy die deurknop moet draai?	☐	☐	☐	☐	☐
Take en opdragte verrig en speel					
Kan jou kind	☐	☐	☐	☐	☐
- opdragte verrig en inkopies doen?	☐	☐	☐	☐	☐
- by 'n motor, speelgoed-motor of skoolbus in- en uitklim?	☐	☐	☐	☐	☐
- op 'n fiets of driewiel ry?	☐	☐	☐	☐	☐
huishoudelike werkies verrig (bv. skoteigoed was, rommel uitdra, stofsuig, werf aan kant maak, bed opmaak, kamer aan kant maak?	☐	☐	☐	☐	☐
- hardloop en speel?	☐	☐	☐	☐	☐

*** Merk asb. enige HULPMIDDELS of TOESTELLE wat jou kind gewoonlik gebruik om hom/haar te help met enige van die bogenoemde bedrywighede:**

Aangepaste toiletsitplek	☐	Flesoopmaker (vir flesse wat voorheen al oopgemaak was)	☐
Bad-sitplek	☐	Toestelle met lang handvatsels (om beter byte kom)	☐
Badreling	☐	Badkamer-toestelle met lang handvatsels	☐

*** Merk asb. met watter bedrywighede jou kind gewoonlik hulp nodig het WEENS DIE SIEKTE:**

Higiëne	☐	Voorwerpe vashou en oopmaak	☐
Uitrek en bykom	☐	Take, opdragte en speel	☐

Ons wil ook graag uitvind of jou kind weens syhaar siekte enige pyn het.

Hoeveel pyn het jou kind OOR DIE AFGELOPE WEEK weens syhaar siekte gehad?

Dui asb. op die onderstaande lyn aan hoe ernstig die pyn na jou mening was.

Geen pyn 0 |---------- 100 Baie hewige pyn

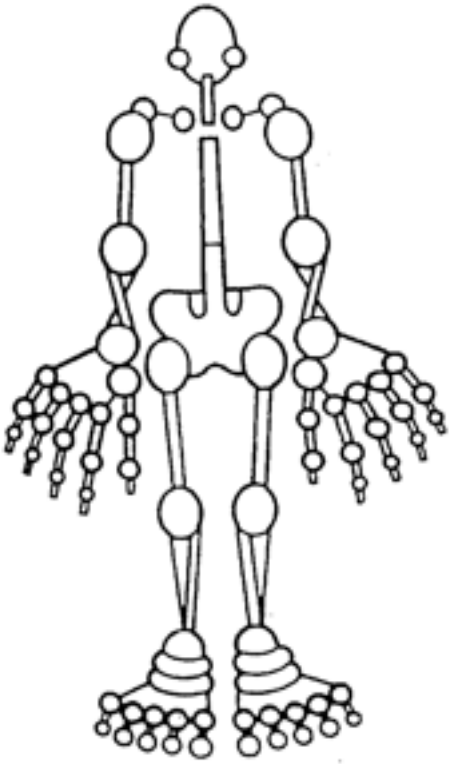
ALGEHELE TOESTAND. Hoe affekteer artritis jou kind? Hoe goed of hoe swak vaar jou kind met hierdie toestand? Merk net een punt op die lyn hieronder om dit aan te toon.

Baie goed 0 |---------- 100 Baie swak

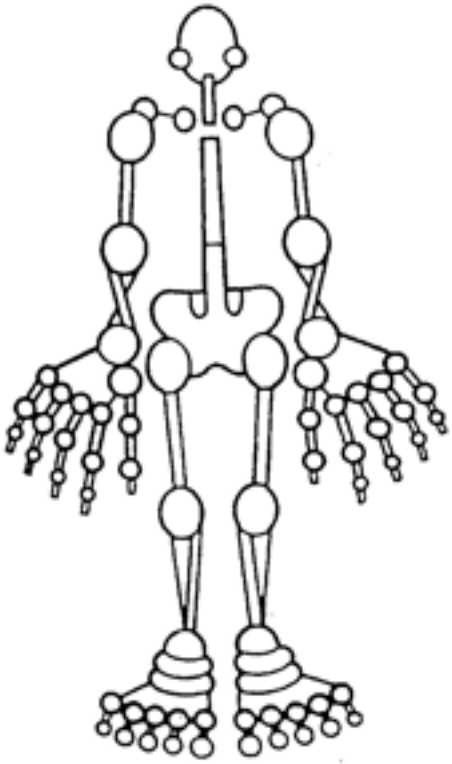
5.6 Data collection sheet

Number	_____
Age at diagnosis	
Current age	
Sex	Male: Female:
Type ofJIA	Systemic / Oligoarthritic / Polyarthritis RF neg/ Polyarthritis RFpos /Psoraitic arthritis / Entethisitis related
Primary caregiver	Mother/ Father/ grandparent/ other
Level of schooling	Gr1 / 2/ 3/ 4/ 5/ 6/ 7/ 8/ 9/ 10/ 11/ 12/ tertiary
Area of residence	
ANA	Positive / Negative Titre:
RF	Positive / Negative Titre:
HLA B27	Positive/ Negative Titre:
Hb	Level:
PLt	Level:
ESR	Level:
CRP	Level:
ALT	Level:
AST	Level:
HIV	Pos: Neg: CD4: ARV:
TB	Prev TB: When: Completed Rx: Current TB:

5.7 Joint Count



ACTIVE



LIMITED

5.8 Consent Form: Participation in study on arthritis in the Western Cape.

Dear Parents:
We are conducting a study on behalf of the University of Cape Town, to find out more details about children suffering from arthritis in the Western Cape. We will be looking at 50-100 children with arthritis.
To participate in this study you will have to give consent for your child's medical information to be evaluated by a doctor who will be attending the clinic to do the research. The doctor will ask you to answer some basic questions to find out details about how your child was found to have arthritis and how it has been treated. We will also ask you to fill in a form, which will give us an indication of how the illness affects your child. Depending on the outcome of the questions we may also want to do an examination of your child's joints. You will only need to be involved in the study once off for about 15 minutes. Your child's medical information is totally confidential and will only be used for the purpose of this study and will not be shared with anyone who is not directly involved in the research. The ethics committee members or auditors may inspect some of the documentation. We will not take any blood tests or x-rays other than what is necessary to provide routine care for your child. If your child is HIV positive this fact will be included in the study, but his or her identity will remain confidential. His or her name will not be used in the study. Please note that there will be no monetary compensation for your participation or cost to yourself.
Your child will receive the same optimal care, whether you decide to participate in the study, or not. You may withdraw from the study at any time. This will not affect your current treatment.
Benefits of the study are that there will be additional information on arthritis available to the western capes' specific population, which may in the future be used to motivate for more extensive treatment to become available. The study may be presented to international congresses, which would highlight the plight of your child and others.
Please feel free to ask us any questions if anything is unclear to you, before signing permission for your child to join the study. Contacts-Principal Investigator- Dr K Weakley 0832977799 drkweakley@gmail.com. UCT ethics committee 021 4066626 shuretta.thomas@uct.ac.za. Stellenbosch ethics committee-0219389207. This research has been approved by both UCT and Stellenbosch ethics committees.
This study is in accordance with the International Declaration of Helsinki and other applicable ethical codes.Thank you,
Dr Chris Scott
I, _____, hereby consent to participate in this
Study project, and for the medical information of my child
_____ , to be collected for this purpose.

Signed on _____/_____/2010 at
_____

5.9 Ethics Approval, University of Cape Town

UNIVERSITY OF CAPE TOWN

Health Sciences Faculty
Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6626 • **Facsimile** [021] 406 6411
e-mail: shureta.thomas@uct.ac.za

21 April 2010

REC REF: 172/2010

Dr K Weakly
C/o Dr C Scott
Paediatrics, Red Cross

Dear Dr Weakly

PROJECT TITLE: JUVENILE IDIOPATHICARTHRITIS IN 2 TERTIARY CENTRES IN THE WESTERN CAPE, SOUTH AFRICA

Thank you for your letter to the Research Ethics Committee dated 19 April 2010.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted until 30 April 2011.

Please submit an annual progress report if the research continues beyond the expiry date. Please submit a brief summary of findings if you complete the study within the approval period so that we can close our file.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the REC. REF in all your correspondence.

Yours sincerely

Signature removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB0000I938

This serves to confirm that the University of Cape Town Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP) and Declaration of Helsinki guidelines.

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

knjoti

5.10 Ethics Approval, University of Stellenbosch

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jou kennisvennoot • your knowledge partner

04 June 2010 **MAILED**

Dr KR Weakley
Registrar
5 Disa Avenue
Observatory
2975

Dear Dr Weakley

"Juvenile idiopathic arthritis in two tertiary centres in the Western Cape, South Africa.

ETHICS REFERENCE NO: N10/05/178

RE : APPROVED

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project on 2 June 2010, including the ethical aspects involved, for a period of one year from this date.

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary.

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 4839907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax +27 21 931 3352

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Approval Date: 2 June 2010 Expiry Date: 2 June 2011

Yours faithfully

MRS MERTRUDE DAVIDS
RESEARCH DEVELOPMENT AND SUPPORT
Tel: 021 938 9207 / E-mail: mertrude@sun.ac.za
Fax: 021 931 3352

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

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