



UCD Centre for Arthritis Research

Edition 11  
Summer 2023

# NewsRheum

Welcome to the Summer 2023 edition of News Rheum. The theme of this edition is Evidence Based Patient Care.

Since our last edition of News Rheum, our researchers and patient partners have been busy with grant applications. The Rheumatology research seminar series continues with a wonderful line up of speakers this year. We are looking forward to hosting our annual conference in November. We hope to see you there! We hope you are well and enjoy this issue of News Rheum. If you would like to get involved, please contact us at:

[patientvoicearthritis@ucd.ie](mailto:patientvoicearthritis@ucd.ie)

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# How Easy to Read is Online Parent Information for Common Pediatric Rheumatic Conditions?

## What is the Problem?

Childhood rheumatic diseases are a group of chronic or long-term diseases. The problem starts in childhood before the age of 16 years. The problem may begin at a very young age in babies or toddlers. Currently, there is no cure for these diseases. The aim of treatment is to stop inflammation and improve quality of life. These diseases are complex. Parents are heavily involved in making decisions about their child's medical care. Parents and children need plain English information in order to understand their disease. The internet is a helpful tool for providing information. This information is not always easy to understand. It is important that complicated information is written in clear language so that it can be easily read.

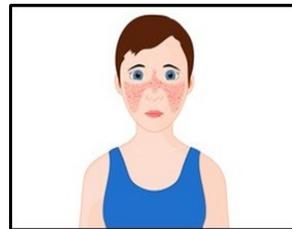


Studio, Phynart, et al. "Wrist Massage. A Male Massage Therapist Puts Pressure on a Sensitive Point on a Kid's

search/2/image?phrase=juvenile+arthritis.

Juvenile idiopathic arthritis affects 1 in 1000 children. Juvenile dermatomyositis (JDM), juvenile scleroderma (JScI), and juvenile systemic lupus erythematosus (jSLE) are rare diseases. All these diseases are complex. There is important information that parents need to understand so that they can recognize if their child is unwell or having a flare. There are many different treatments for each of these diseases. These treatments can be medications or treatments like physiotherapy, occupational therapy, hydrotherapy, and psychology. Parents need easy-to-read information so that they can understand all this complex infor-

mation. This helps them when they have to make decision about their child's needs.



Shutterstock.com. 2022. [online] Available at: <<https://www.shutterstock.com/search/butterfly+rash>> [Accessed 11 January 2022].

## What did we do?

We assessed how easy to read freely available online information is for parents of children with JIA, JDM, JScI, and jSLE. We searched for English-language PDF brochures and web pages written by reputable sources. We included the information written by charities, patient advocacy groups, government sources, educational institutions, and healthcare providers. Information on personal blogs and personal websites was excluded from the analysis. We used the tools we described earlier to get scores for reading ease, reading grade, and the percentage of passive sentences. The information was measured using a standardised tool called the "*Flesch-Kincaid Score*."

The *Flesch-Kincaid Score* measures how readable information is. It uses two variables:

- The average length of sentences, measured by the number of words per sentence.
- The average number of syllables per word

It takes those 2 variables and formulates an overall score. The higher the score, the easier it is to read the information. In other words, a text with a high *Flesch-Kincaid Score*

is made up of short sentences and a words with not too many syllables. Therefore, the information is easier to follow and understand. Currently, the recommended guidelines for reading ease is >70, 7-8th with no passive sentences.

### What did we find?

We found over 40 information sheets about JIA, 6 about JDM, 27 about JScl, and 6 about JSLE. We have summarized the information about these sheets in the table below. This tells us that none of the information sheets were as easy to read as the guidelines recommended. It also tells us that there can be big differences between information sheets. Some of them were close to meeting the recommendations. Others contained a lot of hard to read language. We were surprised to find that the information about was as hard to read as the information about the other three diseases. JIA is much more common than the other three diseases and there is a lot of information for parents online about JIA. We thought that the information about JIA might be easier to read because it is more common so there are more people interested in reading about it.

<b>Disease</b>	<b>Mean Ease (Range)</b>	<b>Mean Grade (Range)</b>	<b>Mean % Passive Sentences</b>
<b>JIA</b>	49.9 (38.5 - 71.9)	10.65 (6.7 - 12.4)	14.61 (4.9 - 31)
<b>JDM</b>	51.5 (38.5 - 71.9)	9.9 (6.7 - 12.4)	22.2 (4.9 - 31)
<b>JScl</b>	47.1 (25.6 - 74.5)	10.8 (6.7 - 14.3)	17.1 (2.7 - 40.2)
<b>JSLE</b>	54.6 (42.7 - 64)	9.6 (7.9 - 11.2)	13.2 (4.3 - 16.3)

### What does this mean?

Plain English parent information for these childhood rheumatic diseases is easy to find online. However, it does not meet current recommended guidelines for reading ease. This means that these information leaflets might not be as helpful to parents as their authors want them to be. It shows that there is a need to develop additional easy-to-read information aimed at parents of children with rheumatic disease. Ideally, these information sheets will be developed with families who have experience with these childhood rheumatic diseases. That will help make sure that the information covers what these parents and families need and better support families in understanding their child's disease.

### About the Author

Dr. Alicia Yavani Kulasingham is a recent medical graduate from the Royal College of Surgeons in Ireland. Originally from Toronto, she is currently in the process of applying for Pediatric Residency programs in Canada, with her goal of eventually pursuing a career in Pediatric Emergency Medicine. She has a keen interest in Pediatric research, specifically in rare Rheumatological conditions. She has presented data at numerous scientific conferences and was a finalist placement in the Clarity in Research Medal at the UCD Centre for Arthritis Research Conference against postgraduate researchers in November 2019.



# **A qualitative systematic review in the attitudes and perceptions of Health Care Professionals in the Management of Fibromyalgia Patients.**

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Most research papers are written with the patient in mind, both in the treatment of their specific disease, in addition to the psychological impact the disease has at the patient level. This Paper, however turns inward and looks not just at the shortcomings among the HCP professionals themselves, but in addition the haphazard management pathway available to HCPs resulting in frustration for the HCPs, but more importantly despair and a sense of hopelessness amongst patients.

The researchers undertook an exhaustive search through all the available literature on Fibromyalgia starting with in excess of one thousand articles, eventually distilling this down to a mere nine articles which shared common traits. This systematic qualitative approach uncovered six key stumbling blocks in the treatment process, which ultimately deprive the patient of a positive experience along the consultation journey.

Chief among the findings were:

- The lead time to diagnosis was lengthy and frustrating for both HCPs and patients alike.
- The symptoms are for the most part vague not helped by the small number of reliable diagnostic tests.
- Gaps in the HCPs training contribute to a reluctance of the physicians to reach a diagnosis.
- The lengthy consultative process leads to a fractious therapeutic relationship.
- Gender bias among male HCPs was observed towards females, with the use of negative descriptors commonplace, such as “complaining Women”

*“They have a profile of complaining which figuratively speaking is more readily accepted by society in women than in men” (Rheumatologist, Briones E et al 2017)*

- Good open communication above all was essential between the HCP and patient during the consultative process, fostering a good “working alliance” (Greenson R 1967)

Further concerns voiced by HCP was a lack of consultation time available to them, thereby depriving the patient of quality treatment. In addition, due to the complexity of the symptoms, the number of consultations exceeds those of other diseases, further fuelling the frustration for both physicians and patients.

While the systematic review has uncovered numerous negative insights, caution by the reader is required given the final sample size of nine papers.

Our recommendation from this systematic review, suggests that HCPs would greatly benefit from further training in patient empathy, coupled with a resolute focus on listening techniques, to enhance the patient/HCP experience.

Further clinical guidelines in the management of Fibromyalgia, will bring about an improvement in both the quality and consistency of patient care, and lead to an altogether more rewarding experience for the HCP professional with their patients.

This patient centric approach will bring significant benefits to patients reducing pain, fatigue, and depression bringing renewed hope for this group into the future.

# **Peoples' Beliefs About Hip Pain and its Care**

*Authors: Travis Haber, Rana S Hinman, Fiona Dobson Samantha Bunzli, Adam Hill, Michelle Hall*

## **Abstract:**

### **Introduction**

People with hip pain can experience difficulty walking, sleeping, working, and doing the things they enjoy. But, people with hip pain often do not get treatments to help them with these difficulties. To better guide people with hip pain to find helpful treatments, we need to use more patient-centred care in health care. To give patient-centred care we need a strong understanding of peoples' beliefs about hip pain.

### **Methods**

This study pulled together and reviewed existing research studies. We included studies that explored middle-aged and older adults' beliefs or expectations about chronic hip pain or the health care they received for it. Articles also had to include people with an average over 45, and 80% or more of the people in the study had chronic hip pain. To find articles, we searched multiple research databases. We excluded studies of people with some conditions that can cause hip pain, such as cancer or rheumatoid arthritis. We then pulled the relevant information from the included articles and looked for common themes.

### **Results**

We included 28 articles involving 352

people with chronic hip pain. We found five common themes across the articles:

- 1) People believed age, wear and tear, posture, and too much sport caused their hip pain
- 2) Hip pain negatively impacted peoples' physical and mental health and family life
- 3) To cope with hip pain people avoided activity or rested
- 4) Often people were given unhelpful treatments
- 5) People believed surgery was the cure for their hip pain.

### **Conclusion**

People thought their hip was damaged and caused by age and wear and tear. As a result, people coped with their hip pain by avoiding things or resting. People were not told about treatments or used treatments that failed to improve their hip pain. People thought that they needed surgery

# **Discovering and modulating mechanisms by which Peptidylglycine alpha-Amidating Monooxygenase (PAM) influences the risk of genetically inherited tissue damage in Rheumatoid Arthritis**

*Prof. Gerry Wilson, Dr. Kevin Sheridan*

*Centre for Arthritis Research, Conway Institute*

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## **Summary**

Rheumatoid arthritis (RA) is a disease in which the immune system attacks the body and affects around 50,000 people in Ireland. This results in swollen and painful joints, which can be severely debilitating. The underlying cause is a mixture of nature (genetics) and nurture (environment). The genetic site rs26232 has been found to be linked with risk of developing severe joint cartilage damage, dependant on which pair of genetic bases are present (CC, CT or TT). Patients with the bases CC at the rs26232 site have more severe disease than those with CT, with lowest damage in TT. Rheumatoid arthritis synovial fibroblasts (RASFs), cells found in the lining of joints in arthritic patients, are more destructive when they have the CC gene code.

works in RASFs, key cells of the joint involved in tissue damage. A better understanding of the causes of RA can help us treat it better, thereby preventing severe joint damage and physical impairment.

This ongoing study at UCD CAR is a HRB funded study recently awarded (€368,000).

To investigate how rs26232 influences RA we looked at the genes beside it. We noticed that one of the genes, called PAM (Peptidylglycine alpha-Amidating Monooxygenase), was present in higher amounts in cells with the genetic marker TT compared to cells with CT, and higher again than cells with CC, suggesting that rs26232 may control the levels of PAM, and that low levels of PAM (as seen in the cells with CC) may explain the greater damage present in CC patient. The role of PAM in RA has not been investigated before. However, our results to date shows that low levels of PAM lead to greater tissue damage. The project will establish how PAM

# RHEUMATOLOGY RESEARCH SEMINARS

We are incredibly grateful to our guest speakers and all colleagues who have attended and participated in the seminar series in 2022. The Rheumatology Research Seminar Series continues in 2023. We hosted a list of incredibly talented speakers in the first half of 2023. Visit our website and twitter page for more information on upcoming seminars.

Speakers for our last three seminars were-

- Dr Virginia Minogue on *"Patient and Public Involvement: a journey through Research and Development"*. [View on YouTube](#).
- Prof Anne Barton, Professor of Rheumatology at the Centre for Genetics and Genomics Versus Arthritis, and Lead at the Centre for Musculoskeletal Research, University of Manchester. The seminar title is *"Pharmacogenomics of Psoriatic Arthritis"*. [View on YouTube](#).
- Seminar featuring the work of researchers at UCD and the Centre for Arthritis Research. [View on YouTube](#). The speakers and topics for the session were:
  - \* Dr Kevin Sheridan - *"The Role OF Peptidylglycine alpha-amidating Monooxygenase In Rheumatoid Arthritis Synovial Fibroblasts"*
  - \* Dr Olga Baron - *"7 @ 1 Blow - How Flies Can Help Us To Learn About Musculoskeletal Pain?"*
  - \* Dr Michelle Hall - *"Does Modifying Joint Load Alleviate Symptoms Of Osteoarthritis?"*

Our next seminar will be on 15 September 2023 , featuring Dr. Rebecca Sadun, Adult and Pediatric Rheumatologist, Duke University.

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## QUESTIONS? IDEAS? WOULD YOU LIKE TO WRITE FOR NEWS RHEUM?

We are always happy to hear from you. If you have an idea to share, a question to ask please do not hesitate to get in touch. We are always happy to hear from people who would like to contribute to News Rheum and what we cover. Get in touch at [patientvoicearthritis@ucd.ie](mailto:patientvoicearthritis@ucd.ie)

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