Paediatric Rheumatology Services in Wales

Arthritis Care Wales, National Rheumatoid Arthritis Society (NRAS) and British Society for Rheumatology (BSR) briefing.

There is no specialist paediatric rheumatology centre or full dedicated multidisciplinary paediatric rheumatology services in Wales – the only home nation without such a centre. Arthritis Care, NRAS and the BSR believe children with arthritis in Wales deserve better. We are calling for a tertiary multidisciplinary paediatric rheumatology service to be established in South Wales and an improved provision of services in North Wales.

Arthritis and children – key facts

- Juvenile Idiopathic Arthritis (JIA) is a severe auto-immune condition which if not properly treated and managed can cause significant, life-long disabilities. JIA occurs when the immune system, instead of just attacking infections, attacks the tissues of the body as well. JIA can cause severe joint pain, swelling and stiffness and other symptoms.
- Having arthritis can have an impact on all aspects of a child’s life – including otherwise routine day-to-day activities, family and social life activities as well as education.
- The fluctuating nature of arthritis presents challenges in terms of schooling and how to manage and limit disruption. Due to the nature of pain, arthritis in childhood, as with adulthood, is often a hidden condition.
- There are 12,000 children in the UK with JIA¹. We estimate there to be approximately 400 children with JIA in the South Wales region.

Why is Paediatric rheumatology important?

- Children with arthritis need access to high quality health and support services to help limit the impact of their condition and to help them reach their true potential.
- A paediatric rheumatology service plays a vital role in:
  - Providing expert, timely and efficient early diagnosis and early intervention.
  - Ensuring skilled multidisciplinary age appropriate care, support and transition.
  - Achieving and maintaining remission to minimise life-long disability and deformity and to preserve normal growth and development.
  - Minimising travel and disruption to education and personal development.
  - Coordinating health, education and social care plans. Providing education and support to children, young adults and families to help them limit the impact of the condition.
  - Implementing national guidelines and agreed local pathways and auditing service performance.
  - Supporting research and trials.
Current Paediatric Rheumatology Provision in Wales

- Wales is the only home nation without a specialist paediatric rheumatology centre. Northern Ireland has a population of 1.8m, compared to 3.1m in Wales, yet it is Wales that lacks a multidisciplinary paediatric rheumatology service. Scotland’s population of 5.2m is supported by two services.
- Currently, an experienced adult rheumatologist at University Hospital of Wales, Cardiff is providing the specialist paediatric rheumatology service for South Wales within 0.25 WTE. There is no formal clinical network and limited dedicated specialist multidisciplinary input. There is a limited visiting service from Bristol provided in Swansea. Some children in South Wales are travelling to Bristol and beyond for their paediatric rheumatology service. In North Wales, a limited visiting service is provided from Alder Hey Hospital, Liverpool.

What needs to happen?

South Wales

- We believe that with a population of over 2 million (over 400,000 children) in South Wales, there is an overwhelming case for a full multidisciplinary paediatric rheumatology service for the region and that such a development is long overdue.
- An NHS England Service Specification paper from 2013 states that in NHS England, there should be one consultant paediatric rheumatologist, two nurse specialists and one physiotherapist and occupational therapist per 1m population (200,000 children)\(^2\).
- With the lack of current provision in Wales, many children are travelling long distances to access paediatric rheumatology, with some children travelling to centres in England such as Bristol and Birmingham. Travelling long distances for children with arthritis can be painful and stressful and can cause disruption to education and family life. Parents have to take time off work and take siblings out of school when they have to travel a long way.
- With JIA alone affecting around 1 in 1000 children before counting other paediatric musculoskeletal and rheumatological conditions, we are concerned that there were only 202 children ‘on the books’ as being treated in Cardiff in 2014. Some children will be being seen in England or by paediatricians in S Wales, however we are concerned others are left untreated with potentially devastating consequences.
- We are aware that the current adult rheumatologist who provides part time paediatric care is due to retire in the next few years. We believe that succession planning should be taken forward in good time so as to avoid a situation of ‘no service’ and believe that recruitment to the role would be made easier if plans are put in place now to develop the service into a full tertiary provision.
- We estimate that it would cost approximately £235,000 a year to deliver a minimum level of the multi-disciplinary team at Cardiff Children’s Hospital\(^3\).

North Wales

- Due to the population size of North Wales, we do not envisage a full dedicated multidisciplinary paediatric rheumatology unit being developed within North Wales. However, we believe there is a significant need to improve paediatric rheumatology provision in the region.
We feel that whilst the current provision of services to children and young adults across N Wales is inadequate and requires development, there is an opportunity to utilise the current service model to develop a much improved service across N Wales.

We are currently in discussion with local stakeholders to develop proposals to support such a development. Options we are exploring include increasing the number of visiting clinics provided from Alder Hey Hospital, the development of paediatric rheumatology specialist nurse roles based within North Wales and the development of transitional clinics within North Wales.

If a new multidisciplinary paediatric rheumatology service is developed in South Wales, we would not wish to see children and young adults in North Wales having to travel to South Wales to access the service. We would wish to see a continuation of provision from Alder Hey for the North Wales region. We would not wish to see children travelling any further than they currently do to access paediatric rheumatology services.

Latest developments

Earlier this year, the Welsh Health Specialist Services Committee (WHSSC) confirmed that they will be undertaking a comprehensive review of paediatric specialised services for the Welsh population and that the review will include an assessment of paediatric rheumatology provision in South Wales.

How you can help...

- Please attend the debate in Plenary on 12 July 2017 and consider voting to support the Motion calling for a multidisciplinary rheumatology service to be developed in Wales.
- Please consider writing to WHSSC to register your support for the call for improved multidisciplinary paediatric rheumatology provision in Wales, to welcome their review and to request notification of their findings.
- Please consider writing to your local Health Board(s) to register your support for the call for improved multidisciplinary paediatric rheumatology services, to seek their views regarding current provision and how they would like to see services developed locally.
- Lastly, please be a champion for children with arthritis at the Assembly and in your constituency.

About Arthritis Care
Arthritis Care Wales is part of Arthritis Care, a leading UK wide voluntary organisation working with and for people with arthritis. Our services include award winning publications; helplines, community info points; mentoring; campaigning and peer support through local branches, groups and an online community. We have also recently launched our 'Get Active for Arthritis' project in North Wales.

Hywel Evans, Policy and Engagement Manager, Arthritis Care Wales

About the National Rheumatoid Arthritis Society
NRAS is the only patient-led organisation focusing specifically on Rheumatoid Arthritis (RA) and JIA across the UK. JIA-at-NRAS, launched in 2014, is a dedicated service for children living with juvenile arthritis and their
families. We strive to improve access to high quality care and services best suited to the individual needs and preferences of all children, young people and their families, wherever they live.

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About the British Society for Rheumatology

The BSR is a professional, clinically-led society representing the full range of healthcare professionals working in rheumatology and musculoskeletal services. Our members include consultant rheumatologists, paediatric rheumatology professionals, trainees, specialist nurses, physiotherapists, occupational therapists, psychologists and GPs with special interest in rheumatology. The BSR’s role is to promote excellence in the care of people with rheumatic and musculoskeletal conditions and to support those delivering it. The BSR and NRAS published a joint report – Rheumatology in Wales, the State of Play at the end of 2016.

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1 State of Musculoskeletal Health 2017 – Arthritis Research UK
2 NHS England, NHS Standard Contract Paediatric Medicine: Rheumatology. Services Specification No. E03/S/b, 2013. Page 5 ‘As a minimum, and extrapolated from BSR guidance for adult rheumatoid arthritis, there will be one consultant paediatric rheumatologist, two nurse specialists and one physiotherapist and occupational therapist, per 200,000 children’
3 From figures calculated from the Scottish Public Health Network (ScotPHN), NRAS estimates that the cost per annum of providing minimum MDT provision at University Hospital Cardiff would be approximately £235,000 including on-costs. This would mean a full time, paediatric consultant rheumatologist, clinical nurse specialist, physio, OT and 0.25 WTE paediatric psychologist.