



Arthritis Ireland
Little Things make a Big Difference

Submission on
Paediatric Rheumatology
in Ireland

As part of Arthritis Ireland's pre-budget submission 2015, we are calling on the Government to ensure that a dedicated appropriately staffed paediatric rheumatology clinical unit of international standards is created to treat children with juvenile arthritis (JA) effectively.

There are more than **1,000 children under 16 years living with JA in Ireland** today. Early diagnosis is vital so that inflammation is brought under control, preventing permanent joint damage and other chronic complications.

However, **Ireland has one of the lowest number of Consultant Paediatric Rheumatologists in Europe** per head of population. The lack of care facilities and allied professionals dedicated to the care of children with arthritis has resulted in a substandard level of patient care and delayed access to vital and potential treatments that can control their inflammation.

We call on the Government to:

Ensure that a dedicated paediatric rheumatology unit is created to treat children with juvenile arthritis effectively.

Arthritis Ireland believes that an additional consultant paediatric rheumatologist and two additional rheumatology clinical nurse specialists need to be appointed. Appropriate allied health professional support would include 2 further Physiotherapists, an additional Occupational therapist, a dedicated Clinical Psychologist and Social Worker would greatly enhance the standard of patient care, improve access to care and reduce waiting lists.

Dedicated Clinical Space

At present, the paediatric rheumatology service does not have a dedicated clinical unit. Instead, the majority of children with JA are seen and treated in various different areas including a very outdated outpatient unit, cramped physiotherapy room and an overburdened shared Medical Day Ward. This limits and delays the time that the paediatric rheumatology team can see patients, as well as leading to a very long, often arduous day for young children and their families.

Paediatric Rheumatology Resources

There are currently just two consultant paediatric rheumatologists. A significant proportion of their time is allocated to general paediatrics rather than dedicating their time and expertise solely to children with arthritis and rheumatic disorders. This arrangement is directly affecting and prolonging waiting times for children with arthritis to be seen.

Waiting lists

The waiting list for diagnosis of children with suspected juvenile arthritis and other rheumatologic concerns is in excess of two years. Although prioritisation by the paediatric rheumatology team at OLCHC means that every effort is made to see the most urgent cases within 12 weeks (based on the strength of a referral by a doctor), this is still unacceptable. There are children on the outpatient system with uncontrolled symptoms for more than two years. These children can be in constant severe pain and at risk of permanent joint deformity.

Recommended standard of care:

The current level of staffing, facilities and waiting times are totally at odds with international best standards of care from the British Society for Paediatric and Adolescent Rheumatology's (BSPAR), which states that children with suspected JA should be referred to a paediatric rheumatology team within 6 weeks of onset of symptoms and should be seen within four weeks of the referral being made.

It is recommended that steroid joint injections are performed within 4 weeks once identified as being necessary. At present patients wait in excess of 14 weeks for this procedure.

Waiting lists for appointments following on from diagnosis can also take up to 6-8 months. Many of these children are starting on medications which require monitoring and frequent evaluation.

Conclusion:

Children are being left in pain and put at risk of permanent joint damage due to a lack of resources and facilities in Ireland. A dedicated, appropriately staffed paediatric rheumatology clinical unit is required urgently to improve the overall standard of care.