

Meeting of the National Screening Advisory Committee (NSAC)

Friday 17 July 2020, via Microsoft Teams

Post Meeting Statement

At its meeting on July 17th 2020, the National Screening Advisory Committee (NSAC) approved the application of the Governance Group of the National Newborn Bloodspot Screening Programme to add ADA-SCID to the list of the 8 conditions currently screened in the existing programme.

Severe Combined Immunodeficiency (SCID) is a group of inherited disorders of the human immune system and, unless treated, is fatal in infancy. ADA-SCID (Adenosine Deaminase Deficiency-Severe Combined Immunodeficiency) is the leading cause of SCID in Ireland with an incidence of 1.3 per 100,000 live births. Infants appear healthy at birth and signs of immunodeficiency appear some weeks or months later. If diagnosed early and treated in a timely manner, the survival rate is approximately 94%.

The NSAC will now recommend to the Minister for Health that the condition be added to the National Newborn Bloodspot Screening Programme.

The Chair of the Committee, Professor Niall O'Higgins, said:

'Before being recommended by the NSAC all applications are assessed by utilising internationally-validated scientific criteria. When evaluating evidence for programmes, the NSAC works closely with a team from the Health Information and Quality Authority (HIQA).

I am pleased to announce the Committee's decision to approve the addition of ADA-SCID to the screening programme. The addition of this condition will be of huge benefit to the children affected and will allow them to be restored to good health.

I wish also to pay tribute to the skill and commitment of all involved in the widely-recognised success of newborn bloodspot screening in Ireland since it was established some 60 years ago.'

The NSAC also considered an application from the Diabetic RetinaScreen Programme to change the existing diabetic retinopathy screening interval from one to two years. The Committee concluded that further detailed scientific evidence needs to be assessed before the application can be progressed.

Notes for Editor:

The National Screening Advisory Committee (NSAC) is an independent advisory committee and will advise the Minister and Department of Health on all new proposals for population-based screening programmes and revisions to existing programmes.

The Committee will play a significant strategic role in the development and consideration of population-based screening programmes in Ireland.

The National Screening Advisory Committee does not have any operational role in the day to day running of any screening programmes. That remains the responsibility of the Health Service Executive (HSE).

Chair of the National Screening Advisory Committee

- Prof Niall O’Higgins

National Screening Advisory Committee Members

- Dr Abigail Collins
- Dr John Ward
- Dr. Mary Codd
- Dr Sheelagh McGuinness
- Dr Velma Harkin
- Professor Andrew Green
- Dr James O’Mahony
- Martina Fitzgerald
- Irene Regan
- John Gleeson
- Dr Susan Kent
- Dr Keelin O’Donoghue
- Dr Ellen Crushell
- Dr Paul D’Alton
- Dr Paul Kavanagh
- Anne Burke
- Jillian van Turnhout
- Professor Michael Rigby
- Prof Ciaran O’Neill

ENDS