ABOUT WILLIAMS SYNDROME

WHAT IS WILLIAMS SYNDROME?

Williams Syndrome is a rare congenital disorder that occurs randomly in approximately 1 per 18,000 births in the UK. It is non-hereditary, caused by a tiny new deletion on chromosome 7 (which includes the elastin gene). It can be diagnosed by a microarray test or FISH test.

POSSIBLE EARLY PROBLEMS MAY INCLUDE:

- Cardiac problems (usually SupraValvular Aortic Stenosis / Peripheral Pulmonary Artery Stenosis)
- Low birth weight
- Raised blood calcium level / Hypercalcaemia
- Difficulty feeding & failure to thrive
- Difficulty weaning
- Hernias and/or rectal prolapses
- Hypertension (high blood pressure)
- Hyperactivity
- Texture intolerance
- Atypical facial features
- Slow weight gain
- Delayed growth & development
- Severe colic and reflux
- Sleep problems and irritability
- Excessive vomiting and dehydration
- Strabismus (squint)
- Hypermobility
- Hyperacusis (acute sensitivity to certain frequencies / loud noises)

LATER PROBLEMS MAY INCLUDE:

- Heart conditions (most commonly SVAS)
- Renal and bladder problems
- Constipation, abdominal pain & diverticulosis
- Aspects of premature aging
- Excessive talking
- Talking in an inappropriate manner
- Over-friendliness with strangers
- Obsessional interests
- Good verbal skills masking low cognitive ability
- Fear of heights, uneven surfaces / stairs
- Mental health problems, anxiety & depression
- Disinhibited behaviour
- Attention difficulties
- High blood pressure
- Scoliosis & musculoskeletal problems
- Constipation, abdominal pain & diverticulosis
- Hypochondria
- Precocious puberty / early menopause
- Difficulties forming / sustaining friendships
- Emotional Immaturity
- Exaggerated emotional reactions
- Poor navigational skills
- Low IQ
- Attention seeking behaviours

CHALLENGES IN TREATING INDIVIDUALS WITH WS

UNDERSTANDING: Enhanced verbal abilities mask poor cognitive abilities – does the person with WS understand what is happening / what is required? Simple language and visual aids should be used where possible and complex or abstract explanations avoided. If they are an adult, do they require a family member (or advocate) to help ensure they understand as per the Mental Capacity Act Code of Practice?

OVERLY AGREEABLE: Many individuals with WS want to please, so if asked if they understand, most will say yes – open questions can often be more successful.

PROCESSING TIME: Individuals with WS need longer to process questions and their subsequent answers, so please be patient.

ELASTIN: the elastin gene is one of the genes affected by WS and this may influence different organs and tissues - the deficiency in elastin can cause problems which do not usually arise until a later age.

ANXIETY: many individuals with WS are highly anxious about medical appointments and may require greater reassurance, or for young children, play therapy may be a beneficial prerequisite. For adults, anxiety tends to increase with age. Consistent care with a named professional often minimises anxiety related with appointments. A referral for Cognitive Behaviour Therapy (CBT) and/or counselling are often useful in the management of anxiety in adults with WS.

ATTENTION SEEKING / HYPOCHONDRIA: This can be common in WS individuals, consultations which include family members can help rule out exaggeration.

MOBILITY: While most individuals with WS can walk, access requirements should be considered as stairs, heights and uneven surfaces are often challenging for those with WS. Younger children may require pushchairs for much longer than an average developing child.

RESOURCES

The Williams Syndrome Foundation (WSF)

An information advisory service with a register of UK WS cases. It keeps members in touch through magazines, events arranged by a UK wide regional network of volunteers, social media and our website www.williams-syndrome.org.uk . The WSF funds research, resources, respite breaks and holidays for adults with WS. It aims to improve the lives of those with WS.

Clinical Guidelines

You can view our clinical guidelines (including WS growth charts) created by our Professional Advisory Panel on our website www.williams-syndrome.org.uk/clinical-guidelines or request a hard copy by contacting our office (contact details below).

Other Guidelines

The WSF also have guidelines for parents, teachers, employers and dentists. Guidelines are available on anaesthesia and for the care of adults with WS for parents and professionals. Leaflets on feeding issues, anxiety in primary aged children and secondary aged children are also available on our website. www.williams-syndrome.org.uk/clinical-guidelines

WSF Professional Advisory Panel (PAP)

The PAP is made up of doctors, psychologists, scientists, therapists, a dentist and a nurse. All members of the panel have been involved in research into Williams Syndrome and are happy to provide advice.

Website

In addition to the guidelines that are available on our website, we have further articles, studies, presentations, blogs, magazines and information available within the members area of our website. www.williams-syndrome.org.uk/joining-wsf

CONTACT INFORMATION

- **Email:** enquiries@williams-syndrome.org.uk
- **Phone:** 0208 567 1374
- **Website:** www.williams-syndrome.org.uk
- **Facebook:** www.facebook.com/WilliamsSyndromeFoundationUK
- **Twitter:** @wsf_uk
- **Address:** Box 103, 5 Charter House, Lord Montgomery Way, Portsmouth PO1 2SN.

40 FACES CELEBRATING 40 YEARS OF THE WILLIAMS SYNDROME FOUNDATION (1980-2020)

REGISTERED CHARITY NO: ENGLAND & WALES: 281014; SCOTLAND: SCO49897

williams SYNDROME FOUNDATION

A guide to understanding Williams Syndrome for health professionals