

40 years of bringing families together

1986–2026

SUPPORT • AWARENESS • RESEARCH

1986

First family meeting

2021

400 members

2026

Around 1,200 members

01 The beginnings

1986

Families come together

The first London gathering leads to the Society. Founders include Sheila Brown, Ian and Lesley Legg, and Don Andrew; Michael Patton advises.

1989

£17,000 for research

Families fund research with support from the Lewis Family Charitable Trust and British Heart Foundation.

1996

A wider network

The Society merges with the Birth Defects Foundation, later Newlife.



First gathering · 1986



Families Day · 2024

02 Building the Association

2011

The NSA is established

Ian Legg, Don Andrew and Michael Patton establish the NSA, with charity manager Peter Clarke.

2012–2013

Families Days begin

National events connect families with each other and specialists.

2014

Research funding goes further

Seed funding helps lymphatic research secure MRC backing.

2018

A whole weekend together

The first Families Weekend deepens connections and learning.

2020–2021

Investing through COVID

Some unused event funds improve systems during the pause. Two separately funded £20,000 seed grants help research attract larger funding.

03 Widening our contribution

2021

Webinars begin

Support reaches families beyond in-person events.

2022

Sharon becomes Chair

Sharon Allsopp takes over as Chair in April.

2022

A specialist clinic opens

NSA contributes £20,000 to the £80,000 raised for the GOSH clinic.

2022–2024

Living with Noonan Syndrome

The study explores people's experiences.

2024

Medical adviser handover

Michael Patton retires; Dr Emma Burkitt-Wright takes over.

2026

Forty years together

Four new trustees and an administrator join; volunteers extend local support.



Thank you, Ian Legg

A founder and former Chair who brought families together. As Ian retires, we celebrate the community he helped build.

2019 · Remembering Mark Legg

Mark, who attended the 1986 gathering, died aged 33. Channel 4's 24 Hours in A&E featured Mark and his family, showing his personality and raising awareness in the UK and internationally. His brother Matthew Legg's London Marathon run in Mark's memory raised over £10,000; with other tributes, the NSA received more than £25,000.

Good Morning & Welcome!

Sharon Allsopp

Chair of the NSA Board
of Trustees



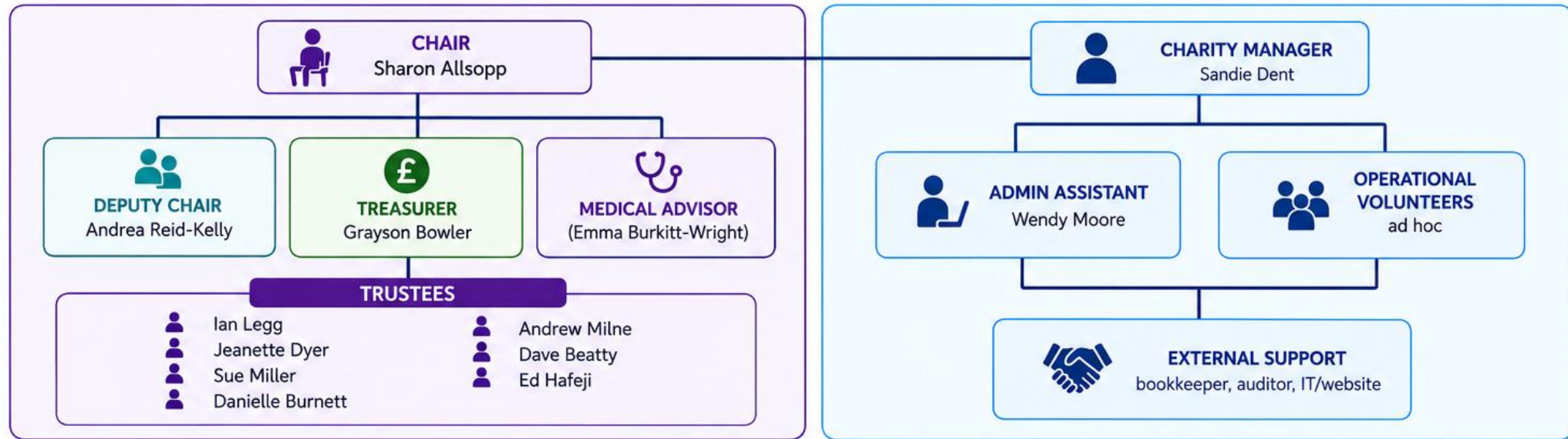
Agenda AM

Time	Agenda Item	Presenter(s)
10:00	Welcome from Chair including Housekeeping	Sharon Allsopp
10:15	Working for the best care for people with NS	Dr. Emma Burkitt-Wright & Dr. Sarah Wilson
10:45	Co-production of an educational toolkit for children and young people with Noonan Syndrome	Dr. Katie Coveney, Dr. Basma Salem, Andrea Reid-Kelly, Sue Miller & Jenny Milne
11:15	Treatment of lymphatic problems in NS with Trametinib, with first hand insight of a patient	Prof. Sahar Mansour & Feargus
11:45	Understanding learning & behaviour in NS	Dr. Shruti Garg & Isabel Turner
12:15 – 13:15	Buffet Lunch (Foyer)	

Agenda PM

Time	Agenda Item	Presenter(s)
12:30	1:1 Appointments with professionals in breakout room	
13:15	Feeding problems in NS	Dr. Keir Shiels
13:45	Heart problems in NS – What patients & families need to know	Dr. Andrew Constantine
14:15	Break (15 mins)	
14:30	Q&A with our panel of experts	Hosted by Sam Weston
15:45	Future prospects for the treatment of NS Spectrum disorders	Dr. Emma Burkitt-Wright
16:15	Wrap-Up, Thank You & Close	Sharon Allsopp

Noonan Syndrome Association



SUBGROUPS



TASK & FINISH GROUP 2026 Legacy Investment Working Group

Lead: Sharon Allsopp

Members:

- Grayson Bowler
- Sandie Dent
- Danielle Burnett
- Ian Legg
- Andrew Milne

MEETINGS CYCLE



Trustee Board Meetings
Quarterly



Subgroup Meetings
Quarterly



AGM
Annually



Task & Finish Group Meetings
As required

2026 NSA News

Received a very generous legacy donation in memory of **Charles & Silvia Sebestyen**

Welcomed four new Trustees to the Board, a new Admin Assistant, an additional medical professional to the Medical Subgroup, and recruited several volunteers to support Communications and Fundraising

Developed a new 'Multi-Agency' subgroup to focus on non-medical support activities and research

Co-production of an educational toolkit for children and young people with NS in collaboration with professionals from Loughborough University

Significantly raised NSA profile by attending external events and conferences (e.g. Rare Disease events)

Ongoing input to NSA International Guidelines

We are pleased to announce the opening of the **Pam Belson Memorial Research Grant offering funding of up to £10k** for research focused on the cardiac manifestations of NS – Deadline for applications is 20th Nov 2026