

Rare Disease has effected my family

Needs of Rare Disease Groups

My name is: Alan Finglas



- My son **Dylan Finglas** - almost 6 years old
- Diagnosed with Multiple Sulfatase Deficiency
Clinically devastating fatal condition
- Our hope is that: The needs & services will be sufficient to give the best possible Q.O.L
- Hope for research & treatment

Multiple Sulfatase Deficiency

MSD Action Foundation

&

SavingDylan.com

Established March 2015

Founder: Alan Finglas

Registered Charity no. 20100957

Charitable Tax Exemption CHY 21493

What do Rare Disease groups need?

Special interest group for Rare Disease in the Dáil

- EURORDIS - the 'Parliamentary Advocates for Rare Diseases'

A network of European & national members of parliament advocating to improve the lives of people living with a rare disease.

- Access to medicines
- Needs and services for patients including Genetics- must be improved
- Action on the National Rare Disease Plan

What can you do?

No.1

- Be a Rare Disease Champion... How?
- Special interest group for rare disease in the Dail & EURORDIS - the 'Parliamentary Advocates for Rare Diseases'

What can you do?

No.2

- National Rare Disease Plan...
- Needs Action & Accountability.

Final Note

- World Rare Disease Day 28th February...
- Tweet & and help with awareness.

