

# SOFT UK Newsletter



## Welcome to our Spring Newsletter From Jan Fowler, Chair of SOFT UK

Dear all,

I am writing this on the 1<sup>st</sup> day of May – Spring is officially here. Not too long until our first Family event of the year in Northampton. I do hope as many of you as possible are able to attend. It is sure to be a great day with lots to do and hear about the world of SOFT UK. We plan to run other events in Scotland and Northern Ireland later in the year.

It has been a busy few months for us all at SOFT since the last newsletter. Launching a new website, developing our podcasts and professional's resources and much more.

Many of you will be aware that SOFT has recently been working with the BBC on the Eastenders storyline about an Edwards' baby. Whilst the storyline was difficult for many to watch and we recognise did not represent everyone's experience, it was done with a lot of empathy and proved a real opportunity to raise awareness about Edwards' syndrome and SOFT itself. We were all a bit cautious about being involved initially.

Concerned that such a sensitive issue could be sensationalised in a soap drama but the team, including the lead actors were very committed to getting things right and listened to the family experiences we were able to share with them.

Sarah Bowell, our new Trisomy Advocate has been getting to know some of you and developing some great resources for families. Do look out for these and give us some feedback if there are other sources of information you would like to see.

Finally, a thank you to everyone who, during March Trisomy Awareness month got involved with things that the SOFT team put together to raise awareness and the inspirational stories of your beautiful children.

I hope you enjoy the newsletter and look forward to seeing you at the family event at the end of the month.

A handwritten signature in black ink that reads 'Jan Fowler'. The signature is written in a cursive, flowing style.

# Podcasts and Zoom



## New Podcasts

Below you will find the upcoming podcasts:

Fiona's story: <https://shorturl.at/IIRWZ>

RPHM: <https://shorturl.at/aotzS>

Introducing Sarah Bowell: <https://shorturl.at/gzHUX>

Working with EE: <https://shorturl.at/fEH38>

Can HIV cause T18: <https://shorturl.at/tNO78>

With the benefits of hindsight:

<https://shorturl.at/afrsW>



## Upcoming Zoom Calls

- Dads: Wednesday 14th June

If you are interested to join these calls, please get in touch with [kate.hart@soft.org.uk](mailto:kate.hart@soft.org.uk)

## New Website!

If you haven't already seen it the SOFT UK website has had a makeover! We are proud to share the new look, resources and information that you will be able to find including:

- Recognition award <https://www.soft.org.uk/recognition>
- Updated resources section <https://www.soft.org.uk/resources>
- Revamped remembrance page <https://www.soft.org.uk/remembrance>
- Family podcasts <https://www.soft.org.uk/family-podcasts>



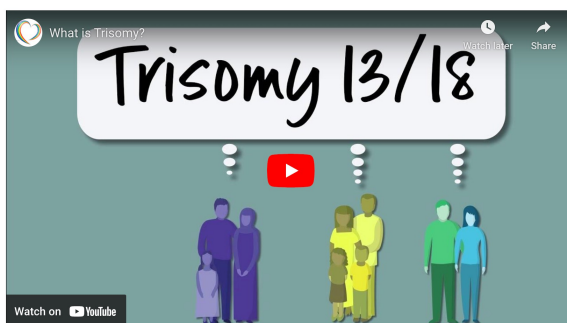
[SOFT UK](#) [Support](#) [About Trisomy](#) [Healthcare Professionals](#) [Families](#) [Remembrance](#) [News](#)



[Donate](#)

Our primary mission at SOFT UK is to ensure families can access support when they need it.

[Get Support](#)



## Jemima's Blog

This is a snippet from a larger piece that Jemima has written which is a guide to becoming a medically complex parent that she is writing for her local area.

<https://www.soft.org.uk/news/managing-relationships>



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## Survey Time – Calling all Trisomy Families

This short survey has been created to collect information about specialist equipment and funding which you have accessed during your trisomy journey, as well as any resources which you think would have been useful to you.

The responses will be used to research support options and compile some helpful information. All responses are anonymous, and the survey should take 10-15 minutes to complete.

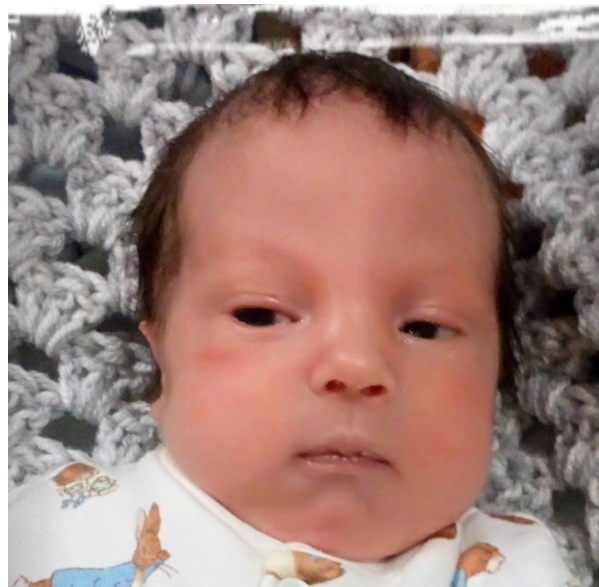
<https://forms.gle/9YPUuKoLnus2E6Vf9>

# Family Stories

## Eloise, 23 Years On

This is a great reflection from a mother recounting her journey with her daughter Eloise 23 years on. Read her story her:

<https://www.soft.org.uk/family-stories-1/eloise-23-years-onnbs>



## Osian's Story

Elizabeth Lockwood has bravely shared her story of her little son Osian who was diagnosed with trisomy 18. Read her story here:

<https://www.soft.org.uk/family-stories-1/osians-story>

# Industry News

## BJM Conference

Last month we had the pleasure of exhibiting at the **British Journal of Midwifery Conference**. This was a great chance to network with midwives and related health professionals from across the UK and get a better understanding of their knowledge of trisomy 13/18 and SOFT UK.

This was the first face to face event held after covid with over 80 midwives and health professionals attending. It is a great opportunity for SOFT UK to raise awareness amongst the professional health community and if you know of other platforms where SOFT UK can make an impact please get in touch [sonia.sankoli@soft.org.uk](mailto:sonia.sankoli@soft.org.uk)



# Fundraising

## Supporting SOFT UK

SOFT UK is dedicated to providing support to families affected by Trisomy 13 and 18, as well as raising awareness. We believe that every family deserves the best possible care and support, regardless of their circumstances.

To continue our vital work, we rely on the generosity of donors like you. Your support can make a real difference to the lives of families affected by Trisomy 13 and 18.

Here are some examples of how your donation could make an impact:

- Help fund our helpline for a family in need of support and advice.
- Help cover the cost of support group meetings and family days, giving families the chance to connect with others who understand what they are going through.
- Help fund printed materials to raise awareness amongst health care professionals, ensuring families are signposted to SOFT UK during or after a diagnosis.
- Keeps our website running, giving families and professionals access to our resources digitally.
- Support our ongoing podcast series, helping to share a wealth of different family stories and experiences.

Whatever amount you can donate, your support is greatly appreciated. With your help, we can continue to make a real difference to the lives of families affected by Trisomy 13 and 18.

**You can donate or setup a fundraiser for SOFT UK at [JustGiving](#)**

# Family Day 2023

## SOFT UK Family Day 2023

Join us at the Hilton in Northampton on Saturday 20th May for a day filled with education, support, and connection with other families affected by trisomy 13 or 18.

We have a fantastic line-up for the day including:

- Sensory room for trisomy children
- Magician in the kids club
- Remembrance room
- Together for Short Lives will be presenting
- SOFT UK Annual Awards

There will also be interactive sessions, family stories, and opportunities to connect with the SOFT team and other families.

Registration is FREE, so please sign up here:

<https://www.eventbrite.co.uk/.../soft-uk-family-day-2023...>