

introducing



... counting the ways

TOFS helps the families of children

born unable to swallow

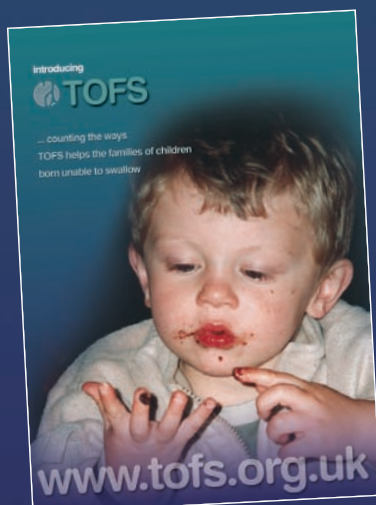


[www.tofs.org.uk](http://www.tofs.org.uk)

## Introducing TOFS ...

*“Parents have to cope with problems for 24 hours a day ... TOFS has been instrumental in bringing families together so that parents can exchange and share ideas on dealing with their children’s common symptoms. Also, sharing a problem with someone who has gone through the same experience is of great help ... it gives hope to parents who sometimes cannot believe that the troubles will be resolved. TOFS is a family affair.”*

Leela Kapila, past Vice-President of the Royal College of Surgeons of England and a past President of the British Association of Paediatric Surgeons



On the front cover: Louis Smith copes quite well with his TOF condition, although he still suffers the occasional “stuck”, when food doesn’t go down.

## What is TOF/OA?

**Tracheo-oesophageal fistula (TOF) and oesophageal atresia (OA) are rare congenital conditions that affect newborn babies. Babies with TOF/OA require intensive neo-natal care prior to corrective surgery, normally within days of birth.**

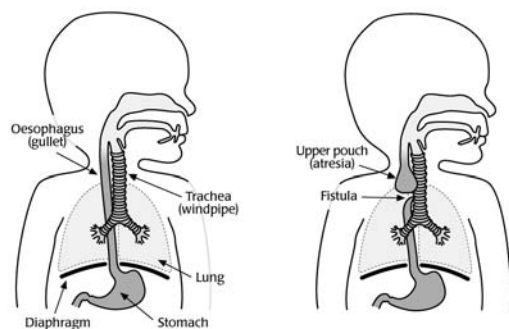
With OA, the food pipe (oesophagus) forms a closed off pouch that prevents food from reaching the stomach. Prior to surgery, this pouch can fill up with food and saliva, which can eventually overflow into the baby’s trachea (windpipe), entering the lungs and causing choking.

With TOF, the food pipe (oesophagus) is connected to the windpipe. Without surgical intervention, this allows air to pass from the windpipe to the foodpipe and stomach. It can also allow stomach acid to pass into the lungs.

Babies born with TOF/OA need to have corrective surgery so that they can eat and drink like other children. This involves removing the oesophagus from the trachea, forming an opening in the bottom of the pouch, and connecting the two sections of the oesophagus.

Although this surgery is usually carried out very successfully, babies born with TOF/OA may continue to have serious problems with eating, as well as respiratory weaknesses.

**One baby in approximately every 3,500 is born with a TOF/OA related condition. Most of these babies are born with both TOF and OA.**



Child without TOF/OA

Child with TOF/OA

Some babies with TOF/OA are also born with problems in other parts of their bodies, such as their limbs or spine. This is known as VACTERL (Vertebral, Anal, Cardiac, Tracheal, (O)esophageal, Renal and Limb) Association in babies with three or more affected parts.

## How does TOF/OA affect children?

**With the benefits of modern medical intervention and the active support of groups like TOFS, the outlook for children with TOF/OA is very positive.**

After surgery, they often have problems with eating and drinking and may also experience other secondary difficulties such as gastro-oesophageal reflux, chest infections and the "TOF cough". They may also need regular medical attention.

Learning to eat and enjoy food can take a lot of time and practice for children with TOF/OA. Because of this, mealtimes can be extremely stressful and time-consuming for families.

**TOFS is a key source of support for families coping with the practical and emotional challenges of living with TOF/OA.**

**"... it is good to talk to others for support, advice and guidance ... it is comforting to know that we are not alone."**

Parent of child with TOF/OA

## What is the TOFS support group?

TOFS (Tracheo-Oesophageal Fistula Support) was set up by concerned parents in 1982 to support the families of children born with TOF/OA and associated conditions. In 1987 the group became a registered charity and a company limited by guarantee.

We offer support and information to parents and carers of children with TOF/OA and we work towards increasing understanding of the condition within health, social and educational services.

We have a membership of around 1100, including many medical professionals with a special interest in TOF/OA.

As a charity we depend on the support of a team of volunteers, several part-time staff and the active involvement of families and friends of children with TOF/OA; much of our organisational and management work is undertaken voluntarily by our members and our Council of Management.

## How does TOFS help?

Learning that their child has TOF/OA can be an extremely difficult time for parents. They will have questions about the condition, the surgery their child needs and how to provide the best care for them. From that first moment, through to sharing the everyday challenges of bringing up a child with TOF/OA, TOFS provides friendship, information and support.

### Family Support

For new members contacting TOFS for the first time, the knowledge that they are not alone and that others have experienced the same challenges can in itself be very reassuring. We know from experience how much peer support can help and we continue to develop our networking service through which members are placed in touch with one another on the basis of locality and their child's particular symptoms.

### Conference

Our biennial conference plays a vital role in supporting and informing our members. These events bring together speakers from a range of clinical and other specialist backgrounds. The conference also offers parents and carers the opportunity to take part in practical workshops.

As well as its educational role, the conference provides an important opportunity for families from all over the country to socialise and share their experiences.

### Phone line

**A direct link to sources of support for parents is available through our 24-hour phone line.**

### Support Through Information

Developed by medical specialists and individuals with practical experience of living with TOF/OA, our information leaflets cover many aspects of the condition. **Our book, *The TOF Child*, is a key source of information for families, carers and medical professionals.**

We visit centres of TOF surgery and other hospitals and distribute leaflets and information booklets to them.

### Chew Newsletter

Our quarterly newsletter, *Chew*, is a valuable source of information to families. As well as updates on our fundraising activities and social events, and articles and features on many aspects of TOF/OA, *Chew* allows parents to share their experiences with each other.

### Website

Our website, [www.tofs.org.uk](http://www.tofs.org.uk), is a global resource which provides easy online access to all our information leaflets. It offers a wealth of detailed information, a general internet discussion forum, and dedicated email lists for interested people from all over the world.

**“It was reassuring to read on your website about other children and adults with the same condition and see them leading normal lives.”**

Carer of child with TOF/OA

### Research

As well as maintaining strong links with key medical specialists, we support scientific research into the causes of TOF/OA and the development of treatments.



Eleanore Derham was born with TOF, but is seen here enjoying a chocolate chip cookie! She can eat most foods now, but still has a TOF cough through the winter.

## Donation Form

Name

Address

Postcode

Tick as appropriate

Please acknowledge this donation

I am a UK tax payer. I have paid tax at least equal to the amount reclaimed and I would like TOFS to reclaim the tax on all my donations.

Signed

Date

## Thank you!

**TOFS, St George's Centre, 91 Victoria Road,  
Netherfield, Nottingham NG4 2NN**

**Telephone 0115 961 3092**

**Fax 0115 961 3097**

**Email [info@tofs.org.uk](mailto:info@tofs.org.uk)**

**Website [www.tofs.org.uk](http://www.tofs.org.uk)**

Dear TOFS,

I want to support your good work!

Here is my donation for £

Name

TOFS can accept donations in the form of cheques and CAF cheques, postal orders (UK pounds Sterling only), and credit card transactions.

Please post donations by **cheque or postal order** to the main TOFS office.

To make a payment by **credit card** please contact the office via email or phone requesting a secure electronic invoice (please do not email your credit card details).

*giftaid it*

Would you like us to acknowledge your donation? Do you want TOFS to recover GiftAid from the Inland Revenue? If so, please fill in your name and address overleaf (this information will not be used for any other purpose).

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## Looking Forward

### Reaching out

We are constantly working towards increasing understanding of TOF/OA and improving the quality of life for the families of children living with the condition.

We aim to maintain and develop closer links with the medical profession in order to raise awareness of TOF/OA. We also want to help carers and teachers to work more effectively with children with TOF/OA by making sure that practical information is available to them.

With increased levels of funding, we can work towards ensuring that the family of every child with TOF/OA can access the funding and support they may need during their difficult early years.

**TOFS provides support which complements that given by medical professionals. We work only in a supportive role, offering emotional and practical support to meet the needs of parents/carers.**

**TOFS ... improving the quality of life for the families of children living with TOF/OA**



Anup and Kalpna Sidhu with Ela

## Making it happen

We are unable to help families living with TOF/OA without funding. Being a charity, we rely heavily on individual and corporate donations.

We organise our own fundraising events and make applications for one-off sources of funding. We also benefit from the financial donations made by the families, friends and local communities of children with TOF/OA. Their support is invaluable, but we also need ongoing funding to allow us to plan our services longer term and work even more proactively.

### Making a donation

TOFS can accept donations in the form of cheques and CAF cheques, postal orders (UK pounds Sterling only), and credit card transactions. To make a donation now, please use the attached form.

Please post donations by cheque or postal order to the main TOFS office. To make a payment by credit card please contact the office via email or phone requesting a secure electronic invoice (please do not email your credit card details).

**“As a chef I know a bit about pressure but I can’t imagine coping with the demands of caring for a child with TOF/OA. The TOFS support group does a fantastic job in helping families cope with the practical challenges that this condition can cause. It is vital that TOFS continues to develop its services, so it is able to respond to the needs of people living with TOF/OA.”**

Anthony Worrall Thompson



## General information

Company registration number 2202260

Charity registration number 327735

### Registered office/administrative office

St George's Centre, 91 Victoria Road, Netherfield  
Nottingham NG4 2NN

**Telephone** 0115 961 3092

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**Email** [info@tofs.org.uk](mailto:info@tofs.org.uk)

**Website** [www.tofs.org.uk](http://www.tofs.org.uk)

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Coordinator

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Jayne Allitt - administrative assistant  
Helene Torr - events co-ordinator

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Birmingham B29 6HR

### Solicitor

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**TOFS**

*Helping children born  
unable to swallow ...*