



The Bungle Pack

kindly supported by **Tracey and Lainey Walters**
————— in memory of —————

Corporal James Walters

affectionately known as '**Bungle**'

TSSS

Turner Syndrome Support Society

The Turner Syndrome Support Society (TSSS) is proud and very grateful to have produced 'The Bungle Pack', in memory of James Walters, affectionately known as 'Bungle'.

James and Tracey, like so many other families, just wanted accurate information about Turner syndrome (TS) so they could make informed decisions. We hope this pack provides information that will help healthcare professionals and families have open, honest and informative conversations.

Life changing decisions, such as whether to continue a pregnancy or not, cannot be based on out-of-date information. No-one knows what the outcome of a pregnancy will be, but they can advise you about the risks and possibilities. How affected your daughter will be can only become apparent as she grows and develops. My experience tells me that families appreciate honesty, even if that means saying 'I am sorry we just do not know'.

From experience, the Society also knows that there is a high miscarriage rate in TS pregnancies. The loss of a baby is very difficult, but, knowing that the baby would have been more severely affected by TS, does provide some comfort. Generally, the babies who survive to birth lead happy, healthy lives. Hence our third booklet on caring for women with TS during pregnancy is important, because having access to the best care means they have the best hope for a good outcome.

Our heartfelt thanks to Tracey and Lainey Walters for their kindness and generosity at a very difficult time. Our thanks also go to the TSSS members who shared their personal stories to help others, and to the healthcare professionals for their time and expertise.

Arlene Smyth Executive Officer of the TSSS

In March 2013, Tracey and James Walters were so pleased to be expecting their first child. James, affectionately known as 'Bungle', had been in the army for 17 years and served in Iraq, Northern Ireland and Kuwait, before five tours in Afghanistan.

At 13 weeks the baby was diagnosed with Turner syndrome (TS), and James immediately became proactive, determined and passionate, ensuring the couple knew everything they could about the condition before the baby was born.

On the 26 April 2014, James, aged 36 years, was killed in a tragic helicopter crash in southern Afghanistan. Lainey was aged just five months and nine days.

“James was extremely passionate about TS and made sure that we were as prepared as we could be for all aspects of Lainey's condition. He would be immensely proud and completely overwhelmed at how far his baby girl has come, and to know that the money raised in his memory is making a difference, by educating parents, saving TS girls' lives and supporting individuals with TS, their families and healthcare professionals.”

Tracey Walters



Further information

Turner Syndrome Support Society

www.tss.org.uk

Turner Syndrome International Group

www.tsint.org

Acknowledgements

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Dr Stephanie Curtis, Consultant Cardiologist, University Hospitals Bristol NHS Foundation Trust

Dr Melanie Davies, Consultant Obstetrician and Gynaecologist, University College London Hospitals NHS Foundation Trust

Dr Mollie Donohoe, Consultant Physician, Royal Devon and Exeter Foundation Trust

Jane Fisher, Director, Antenatal Results and Choices

Dr Helena Gleeson, Consultant Endocrinologist, University Hospitals Birmingham NHS Foundation Trust

Sheila Heslam, Services Director, Down's Syndrome Association

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Dr Anthony Price, Paediatric Endocrinologist (retired)

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Dr Gordon Watt, Consultant Paediatric Podiatrist at Glasgow Caledonian University (retired)



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