

My Blood Thing

Jo McIntyre

My history

- 1971-1995 - Usual childhood illnesses
- October 1995 - TTP Diagnosed
- August 1997 - 1st Relapse
- April 1999 - 2nd relapse
- August 2003 - 3rd relapse

- What is TTP?

- Does ANYONE understand what this feels like?

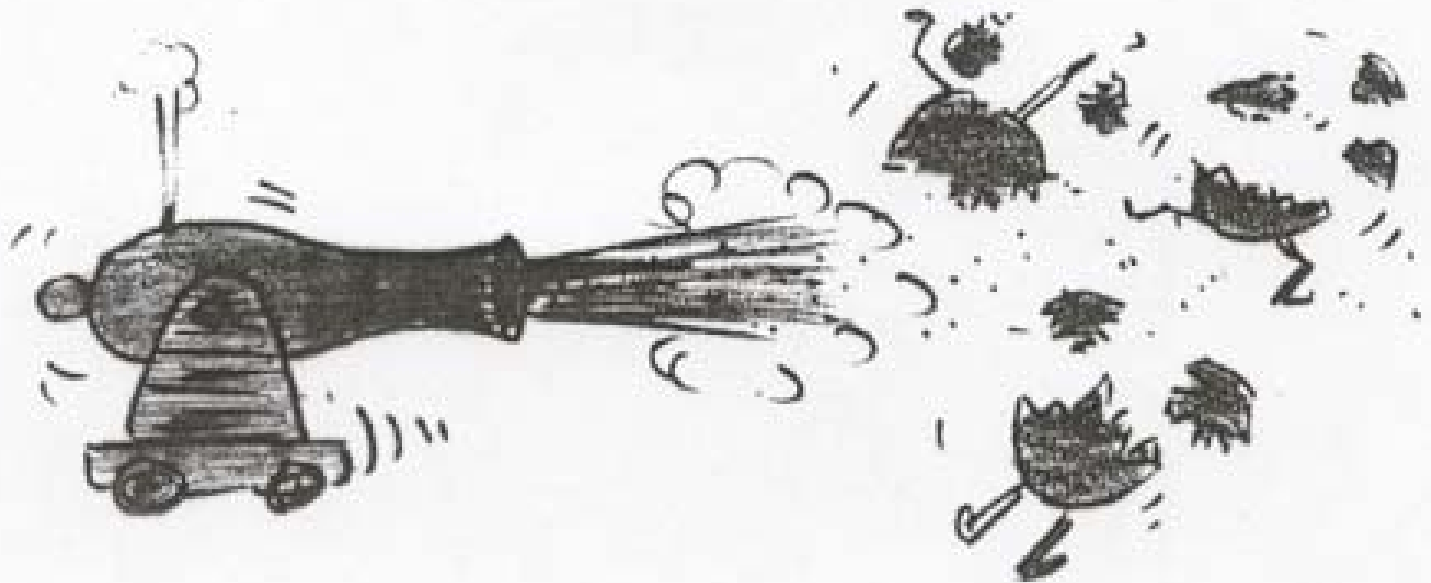
What is Thrombotic Thrombocytopenic Purpura?

- Platelets clump together
- Platelets form small clots, (typically in the blood vessels supplying the brain and kidneys)

- As a result, platelets are consumed
 - The number of platelets circulating in the bloodstream falls dramatically.
- The clots damage red cells as they pass through

Also....

Red cell fragmentation



And...



The science bit



Characteristics



Poor kidney function



Running a temperature

Bizarre neurological behaviour



Characteristics?

Bruising - (overt bleeding rarely)

Neurological symptoms

Renal impairment

Fever

Visual problems

Abdominal pain

Who gets it?

Between 1 - 4 in one million per year

Male and female

Any age although typically 30-40 yrs

Why?

The processing of von Willebrand factor, a protein normally found in blood, is impaired and as a result abnormally Large forms of the protein circulate.

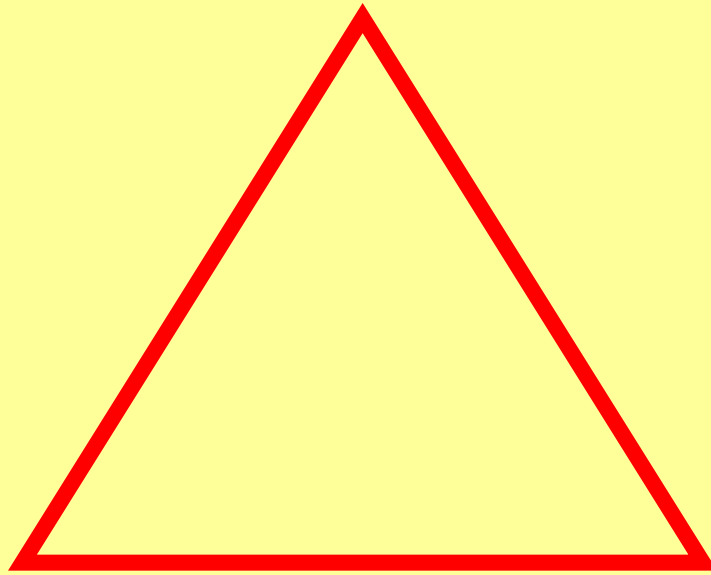
The enzyme responsible for this is likely to be the ADAMTS13 cleaving Protease

(Fairy Fairy plasma)



Treatment?

- Daily Plasma Exchange -
 - Minimum of 7 days
 - FFP
 - Cryo-depleted FFP
 - Immune suppressants to affect the underlying disease process
 - Rituximab



the Giving of Platelets is contra -
indicated in TTP and will seriously
compromise recovery

Does Anyone Understand?



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NEWS

TTP Bruises new poll vo

My name is Jo and in October 1995, aged 24 and having had a fairly healthy childhood I became ill with what was diagnosed as Thrombotic Thrombocytopenic Purpura (TTP).

I was brought back to full health by Plasma Exchanges using Heamofiltration, and Steroids.

In August 1997 I again became unwell - noticing the pinprick rash - caught it early enough for Plasma Exchanges to be effective - again using Steroids to help it along. Within 6 months I was back in full time work.

Once again in April 1999 I relapsed but thankfully noticed quickly enough to get good results from Plasmapheresis and Steroids, Once again I was back at work by the Autumn with no long term after effects other than a bad memory.

I thought Id seen the back of it and was just starting to relax a little when in late August 2003 and with over 4 years remission under

TTP Network

- 257 members listed in Feb 06
- 349 members listed in Apr 07
- Worldwide
- Regular contributors
- Information for patients, families and medical staff
- Message board available for viewing or contributing
- Website re-launch due Aug 07

Zoe's Wish

A charity set up to help patients with the logistics of receiving treatment Zoë sadly died of TTP in Jan 2001 after a 14 month fight.

www.zoeswish.co.uk



The screenshot shows a web browser window displaying the homepage of Zoe's Wish. The browser's address bar shows the URL <http://www.zoeswish.co.uk/>. The website features a navigation menu on the left with links: About Zoe's Wish, How can you help, Can we help you, Our latest News, and Contact us. The main content area includes a welcome message, a description of the charity's mission, and a call to action for supporters. A date indicator shows 'Tuesday 8 June'. There is a technical error message: 'Error Loading Data File textdata2.txt Check parameter 'tla''. At the bottom, there are links to online shops, a 'Donate online' button, an 'Ask for Help' button, and a 'Do something amazing-Give Blood' button. The footer contains the copyright notice: '© 2004 Zoe Dunn Memorial Fund registered charity number 1092483'.

Zoe's Wish
Easing the burden of illness

About Zoe's Wish
Welcome to the **Zoe Dunn Memorial Fund** website. This site is for anyone who wishes to know more about the work of the charity in addressing the needs of the many people, young and old, around the country who depend on regular life-saving treatment at hospital or at a specialist treatment centre

Whether you are a supporter of our work, a hospital or treatment centre, doctor or patient, or you know of someone we may be able to help, we hope you will use this site to access the information you need. to report any problems with any part of this site please contact the web administrator

Tuesday 8 June

Error Loading Data File textdata2.txt
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Visit our online shops
Marks & Spencer, mfi

Donate online

Ask for Help

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Life after TTP?

- Better diagnosis
- Protease measurement
- Treatment guidelines
- Reciprocal treatment arrangements
- TTP study group
- Patient help groups

TTP Patient Day

September 2007

London

Thank you