



the tuberculosis survival project

helping people with TB/MDR-TB to help themselves

TBSP Monthly Newsletter: AUGUST 2007

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It is Good to Talk: The ICN's 'TB Patient' Talk Forum

The Tuberculosis Survival Project (TBSP) announces a new function available on the project website (www.tbsurvivalproject.org). TB Patient Talk is an online forum run and moderated by the International Council of Nurses. The forum is for individuals living with TB or MDR-TB, or who have had TB or MDR-TB in the past.

This platform provides an opportunity for people to discuss their experience of the disease. It might be relating to TB treatment issues, concerning social and workplace support, changes in the community, or other people's reactions to someone after TB diagnosis, and personal matters such as fear of isolation.

TB Patient Talk is very easy to use. Go to the menu on the left hand side of the TBSP website and click on 'TB Patient Talk'. Those wanting to use the site will need to register before using the facility, but it is very easy and fast to do.

Once logged in users can either comment on existing topic postings or start a new topic posting of their own. TB Patient Talk is an excellent tool. If you are an organization with a website that patients use, then why not create a link of your own so that others can learn of and participate in this important forum.

The link is: <http://icn.ch/cgi-bin/ubb/ultimatebb.cgi?ubb=forum&f=12>

'TB Tips' Booklet Due to be Published: Sept 07

A new 32 page booklet called "*TB Tips: Advice for People with Tuberculosis*" is due to be published at the end of September 2007 by 'Don't Panic Press'. The booklet brings together in one place the popular 'TB Tips' that first appeared in highly acclaimed 'Tuberculosis Survival Handbook'. The tips are based on real patient experience of having TB. It will be available to order free of charge for patients from the TBSP website.

Paul (Mayho) Thorn, author of the original book, and the Project Director of TBSP said; "I am so glad this little booklet will be produced. The 'TB Tips' are one of the most popular features in the Tuberculosis Survival Handbook. This booklet contains information that is really relevant to the patient. Now that this information has been condensed into an easy quick reference guide, I hope it will be even more accessible to those who need it."

Introducing Seonai Chongrak's New Web Column

Welcome, everyone, to my world! In this regular web column, I will share my experiences of having and living with TB with you, my readers. The journey has been, and still is, a long one and my intention here is not to bore you to death with tales about myself, but to allow you an insight into my thoughts and to see just how dramatically TB affects the sufferer's life. These ramblings will, I sincerely hope, help those just diagnosed with TB, those who've had it before, those who still have it and the health professionals who deal with it. And we're not going to be depressing here, just telling it like it is!

Me... I'm a normal (fairly!) woman, brought up in Scotland, I have a University degree, I am a journalist and a mother and I have a great passion for all things South East Asian. I was first diagnosed with TB in Scotland while working for the Glasgow Herald and had a relatively easy time of it. Two weeks of treatment and I was back to work and I seem to remember feeling reasonably well. It's likely that I got TB in Asia but it's also just as likely that I picked it up in Scotland! Most people are unaware that there is a lot more TB in Britain than they might want to believe.

I got over that episode and forgot about the dreaded disease. After a spell of working for the London media my son and I headed out to Asia again and I started working for various magazines. Life was sweet. I remarried and went to live on a small tropical island in Thailand. About two years ago I started to cough. It went undiagnosed for a year with doctors telling me it was hay fever etc and health continuing going downhill fast. By June last year I was coughing up a freezer bag full of disgusting green stuff a day, so ravaged by the TB that I had no appetite, lost loads of weight and was lying on the sofa from morning to night believing the end of my life was near. And it was. My husband dragged me to the local hospital again, and this time I was so bad that they physically carried me off the island to a mainland hospital. After a month, friends and family shipped me back to Britain and a new journey began.

I currently have approximately 25% of my lungs functioning well, I have recently come out of an eight-week hospital stay, I can't walk up hills or stairs and even on flat ground I have to sit every few meters. Yesterday my consultant called me and told me that surgery to remove a massive cavity in my right lung is imminent. I am still on the medication and will be for another year as far as I know. But... guess what, I'm feeling positive, the Grim Reaper seems to have left me for now and I'm going to heal myself at least mentally – because that is REALLY important.

“Seonai's World” is a NEW regular feature of the TBSP website. Her second column is available online to read now! Log onto www.tbsurvivalproject.org and bookmark the page. You can also email Seonai via the website with any questions or comments by using the link provided at the bottom of her page.

Can You Provide 'Country Specific Information'?

One of the aims of the TBSP has been to collect country specific information that may be useful to TB/MDR-TB patients in their own region. It has been difficult getting organizations to contribute data for this function. The world is a big place and the thing is that we don't have the manpower to collect all of this information ourselves - we really do need your help!

If you have any projects that you would like TB patients to know about, then please do tell us about them, and provide us with a few paragraphs outlining the initiative. We can help inform TB patients what is available by way of services or other assistance in their own country.

Did Someone Say Something?

Quote: "She looked without interest at my hair, which had been painstakingly arranged in flat curls close to my head, and said, "It's a rule of the Sanatorium that all incoming patients must have their hair washed." This she proceeded to do, aided by a great deal of green soap, her own strong fingers, and more boiling water. "At least she didn't delouse me," I thought bitterly as she hauled out the dryer. The dryer was very hot and had enough force to strip the spring growth from any tree at fifty yards.

When my hair was as dry as excelsior the nurse handed me a comb and mirror. One glance at my exploding head and I felt like breaking the comb in little pieces and throwing them over my shoulder. I made a few futile dabs but it was like trying to part and arranging a thistle. The nurse offered no suggestions. She put away the bath things, then wheeled me down the hall into a four bed ward."

Extract from "The Plague and I" by Betty Macdonald, published 1948. The book describes her personal experience of her time in a TB sanatorium. Well worth reading for her very funny descriptions and observations of other TB patients and the staff caring for her.

Do you have something to say?

If you have a story, any comments about this newsletter, or something else that you want to share, then you can send an email to us via the project website at www.tbsurvivalproject.org.

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