

Speech Given at ICF Convention 2010

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Early one Thursday morning a few weeks back when I was scrambling to leave my house on time so I could catch the 625 am ferry to Seattle, thoughts of the upcoming ICF convention popped into my head. I was thinking that this would be the 11th convention I have spoken at and I need “new material” to keep things interesting. Then it dawned on me that I have never really dissected my medical regiment for you. I usually gloss over it quickly at a branch meeting or convention or talk about what the average patient does. In the world of Thalassemia I am considered a senior citizen – so we may have more in common than you think. The average life span of a person with Thalassemia is 31 according to research put out by the Cooley’s Anemia Foundation. I am not sure if this is 100% accurate or if I want to believe it. I am sure this number increases if you are one of the fortunate patients of Dr Vichinsky’s. So I thought that maybe it was time I give you a very close look at my medical life and regiment– I will admit that it truly is an uphill battle.

To start I went over my calendar and closely examined the last three months – June, July and August and figured out how much time I spend on medical care. Because Thalassemia affects the entire body I categorized my care based on the systems affected:

Hematology – everything blood related:

6 blood TX – 12 units of blood – 43 hours

Blood Tests which include my pre-tx type and cross match and Shots – 1.5 hrs

Doc appt with my Hem – 30 minutes

45 hours

Chelation therapy which is something I do to get rid of excess iron which results from blood transfusions:

1590 Hours of wearing the Desferal Pump

12 hours mixing Desferal and organizing supplies

Cardiology – heart failure is the #1 cause of death and I have a complex cardiac history including 2 incidences of congestive heart failure, a dx of pulmonary hypertension since resolved and a cardiac clot.

Echocardiogram, 2 EKGs, 2 Cardiology appts. – **3 hours**

Gastroenterology:

Follow-up Doctor appointments: **2 hours**. I had 3 endoscopy in 9 months – Pyloricstenosis

- **Dermatology:**
2 Dermatology appointments – r/o melanoma; wound care biopsy and 6 stitches; follow up – **4 hours**
- **Research Studies:**
 - Osteoporosis - 1 week wearing an Actigraph 24 hrs a day to monitor joint movements I have the bone age of a 71-year-old woman – riddled with Osteopenia, close to osteoporosis. Arthritis is in my back, hips and other joints.
20 minutes a day standing on a vibrating platform – **28 hours**
 - Trip to LA – Oral Glucose Tolerance Test to check for diabetes and MRI study of iron storage in the pituitary gland, pancreas and heart – **9 hours**
= 37 hours
- **Alternative Medicine – immune system – infection is the second leading cause of death among people with thalassemia,**
Acupuncture – **5 hours**
- **Pain Management:**
 - Chiropractic – 12 visits adjustments, traction, muscle therapy– **4 hours**
 - X-Rays – back and hand – **30 minutes**
 - Physical Therapy – visits to the therapist and home exercises - **17 hours**
 - Pain Doctor – **30 minutes**
= 22 hours
- **General Care:**
 - Appt with primary care – annual physical – **1 hour**
 - 16 medications = 30 pills a day – organizing meds every Sunday – **3 hours**
 - Traveling to medical appts – **39 hours**
 - Paperwork, paying bills, making appts, phone calls etc – **10 hours**
=53 hours

Grand Total 183 hours (61 hours a month) + 1590 Hours of wearing the Desferal Pump

The most difficult part of having Thalassemia is of this disease is that you NEVER get a break – you may do all the things on the annual comp care list only to start it all over again. Of course my reward is that I am still here talking to you, but sometimes when I get down I wonder “is it all worth it? Am I worth it?” This past year has been a challenge for me – both health wise and otherwise I have had my share of breakdowns – but it is worth it. We lose close friends every year – this year I lost one of my very best.

Beyond the funding – which is vital, you provide me with a sense of unity, caring and love when I am around all of you. You represent what family is and what family provides– comfort,

familiarity, love, acceptance, and a sense of belonging. ICF members are kind, generous, and sincere. This helps me more than you know when times are tough. So for all of this and more I thank you from the bottom of my heart on behalf of all of the patients and families.

God Bless you all.

For more information on how you can help or donate to Thalassemia patients, contact



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