

# Trials of a Wallie

Ron Ternoway

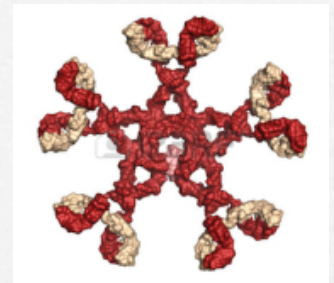
Halifax, Nova Scotia

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# What is Waldenstrom's Macroglobulinemia?

- ❑ one of over 60 kinds of non-Hodgkin lymphoma
- ❑ incurable but treatable
- ❑ rare - 5 new cases per million each year
- ❑ more common in men, average age at Dx - 70
- ❑ cancer cells may be lymphocytes or plasma cells, or both
- ❑ bone marrow-based - 'walks the line' between MM and CLL



# What did my WM feel like to me?

- ☐ fatigued all the time, losing weight
- ☐ night sweats
- ☐ nose and gum bleeds
- ☐ numbness in soles of feet
- ☐ blurred vision





## What did my doctors see at Dx?

- ☐ hemoglobin < 110 (normal 140-180)
- ☐ IgM 62 (normal range 0.5 - 3.0)
- ☐ elevated blood serum viscosity
- ☐ enlarged spleen & lymph nodes in torso
- ☐ 'sausaging' in retinas (retinopathy)
- ☐ Waldenstrom's cells in bone marrow





# What were my Tx options in 2007?

- ☆ ☐ **Plasmapheresis (PP) - temporary reduction in IgM**
- ☐ **R-CHOP**
- ☆ ☐ **Rituxan**
- ☐ **Fludarabine**

**Tx - PP to reduce IgM, followed by 4 doses Rituxan**

**All I got was THE FLARE!**



# What else did we try?



## Therapy

Fludarabine x 4

Fludarabine x 3

Aranesp x 6

CyBorD x 6

## Result

4 years 'remission'

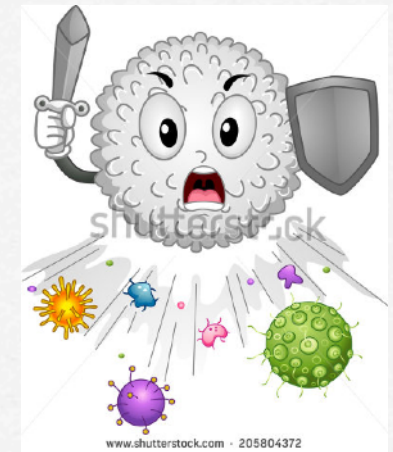
relapse < 6 months

no change in anemia

relapse < 3 months



# WM and autoimmune disorders



- ❑ **Wallies are susceptible to autoimmune disorders, and it may be linked to the same MYD88 mutation, present in over 90% of us, that has led to the success of Imbruvica in treatment of WM.**
- ❑ **In 2014 I developed wAIHA (warm Auto-Immune Hemolytic Anemia) - my IgG marks healthy red blood cells for destruction. It may have been caused by my second fludarabine therapy.**

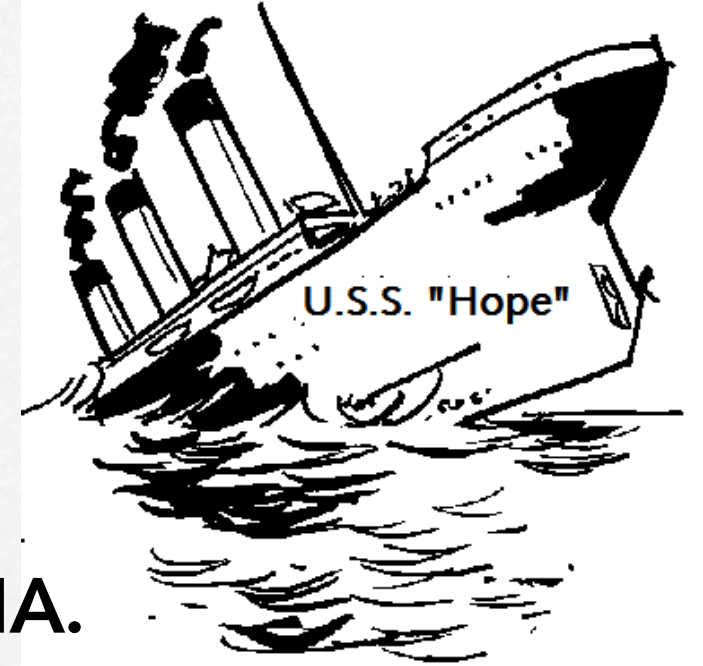
# Treading Water - 2013 to 2014



- ❑ My second fludarabine treatment made my bone marrow incapable of producing anything but platelets.
- ❑ I developed chronic neutropenia, and was on self-administered Neupogen injections for 18 months.
- ❑ I became transfusion dependent, relieved during 6 months of CyBorD (cyclophosphamide, bortezomib, dexamethasone). Immediate relapse and another 6 months of weekly blood transfusions.



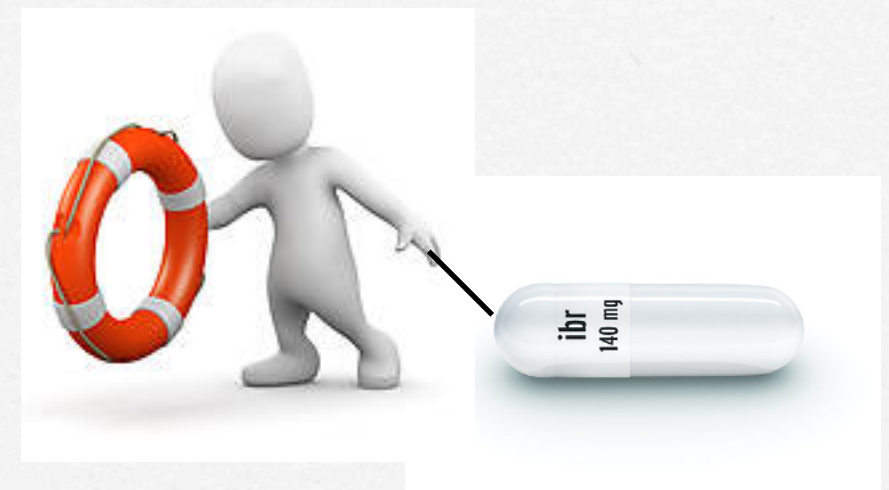
# Desperate Straits - 2014



- ❑ Prednisone failed to impede my warm AIHA.
- ❑ Splenectomy failed to impede my warm AIHA.
- ❑ Chronic high bilirubin (all those dead red blood cells slaughtered by my spleen) led to total blockage of the bile duct, and ultimately removal of my gall bladder.
- ❑ I continued to receive 2 or 3 units of packed red blood cells every week or two.



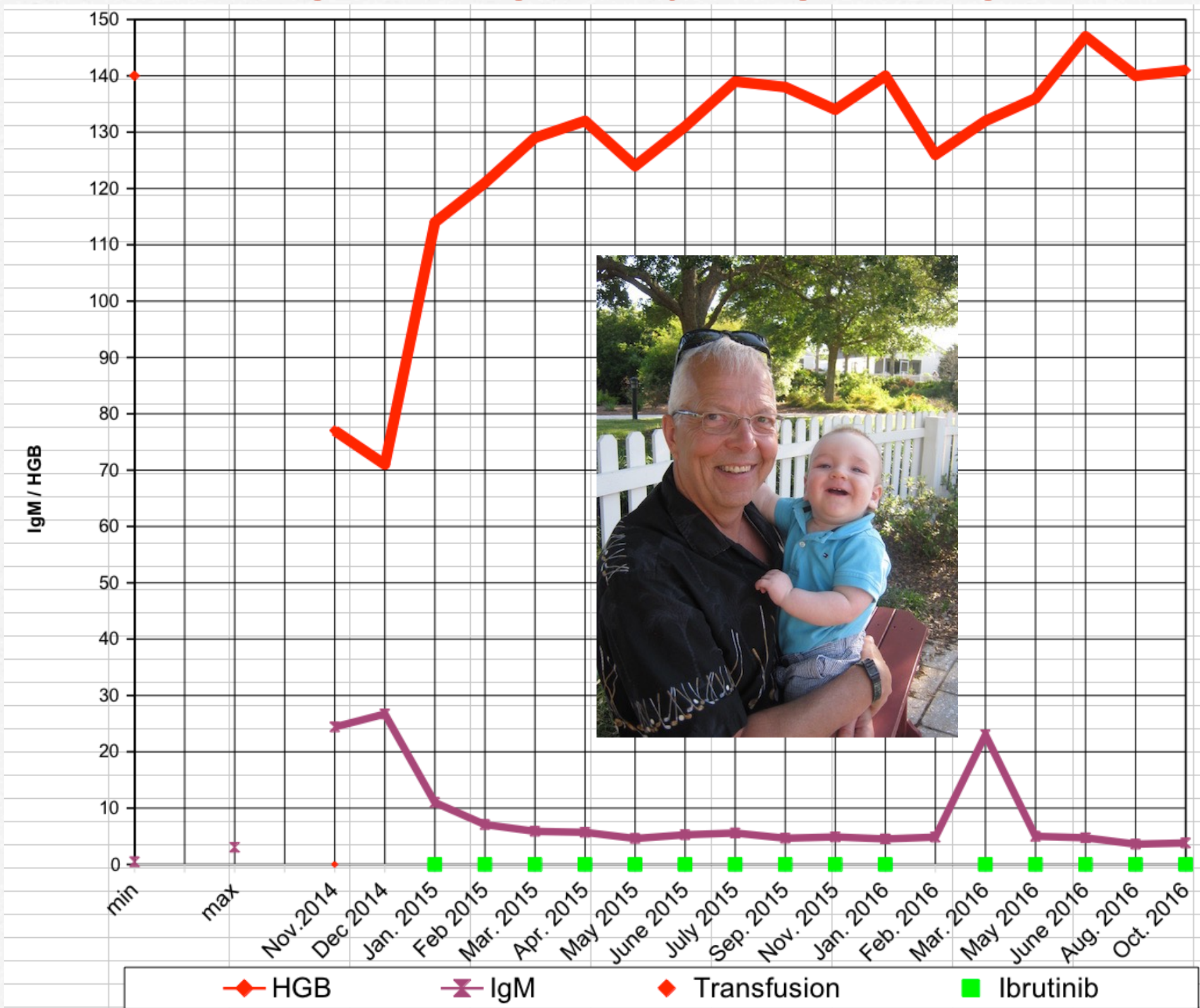
# A Lifeline for Christmas!



- ❑ WM clinical trial of drug ibrutinib offered in Halifax.
- ❑ Last of 30 Wallies worldwide accepted into my trial.
- ❑ Began trial December 17, 2014.
- ❑ Within 4 weeks, hemoglobin up from 70 to 110.
- ❑ Within 4 weeks, IgM down from 27 to 11.
- ❑ No more transfusions, no more prednisone!



# A New Normal for Me





# My (Down-) Side Effects

- ❑ increased blood pressure
- ❑ continual drop in platelet count
- ❑ brittle, ridged nails
- ❑ deep skin cracks on fingers, toes and heels
- ❑ muscle cramps in hands, feet and calves
- ❑ joint pain - knees, lower back
- ❑ easy bruising, scars slow to heal
- ❑ frequent respiratory infections





# My (Up-) Side Effects

- ❑ energy, enthusiasm, and optimism
- ❑ frequent random acts of kindness
- ❑ irresistible urge to climb the stairs to our apartment after a swim and a one-hour walk in the woods
- ❑ desire and ability to travel
- ❑ buying green bananas and long-playing records
- ❑ clinical response to those beautiful women in their summer finery





# The WM Community



- ❑ WM Foundation of Canada - WMFC - provides support and education to Wallies and their families across the country. WM support groups are active in Vancouver, Calgary, Toronto, Ottawa, Montreal and Halifax. I am the support group leader for Halifax, where we have over 20 Wallies, including 7 on the Imbruvica - Rituxan WM clinical trial.
- ❑ WMFC.CA features a Canadian Lifeline, where Wallies with questions can contact veterans. I am the Lifeline contact for Imbruvica and Velcade.



# NS WM Support Group







**Thank you, Clinical Trial, for saving Grandpa!**



# The Punchline



Thanks to my clinical trial, I have gone from a depressed, transfusion-dependent husk of a man to a positive, energetic, relatively fit 65-year old who carries his grandchildren on his shoulders for blocks, and swims and walks 3-5 miles every day.

*Priceless!*