

# A Data Tracking Journey

From Chronic “Unknown” Illness  
to *Crystal Clear* Diagnosis

in 12 months

Quantified Self Conference  
October 2013, San Francisco

# Unknown Chronic Illness 2006 - 2007



Myalgia

Exhaustion

Exercise  
Intolerance

Recovery Year – Bali, Indonesia & Chengdu, China

# Unknown Chronic Illness - June 2012





# Lost in Complexity of Symptoms

## Brain

Lump on Head

Spark and  
Acute  
Headaches

Emotional  
Extremes

Stress

Insomnia

Altered  
Consciousness

Dizziness

Short/ long  
term memory  
loss

Brain Fog

## Gut

Diarrhea

Constipation

Nausea/  
Vomiting

Stomach Ache

## Nervous System

Numb Limbs/  
Tingling

Loss of  
Neuromuscular  
Control

Neuropathy

Weak Muscles

## General Flu-ness

Exercise  
Intolerance

Stiff & Aching  
Joints

Stiff Neck

Myalgia

Intermittent  
Fever

Weight loss

Exhaustion



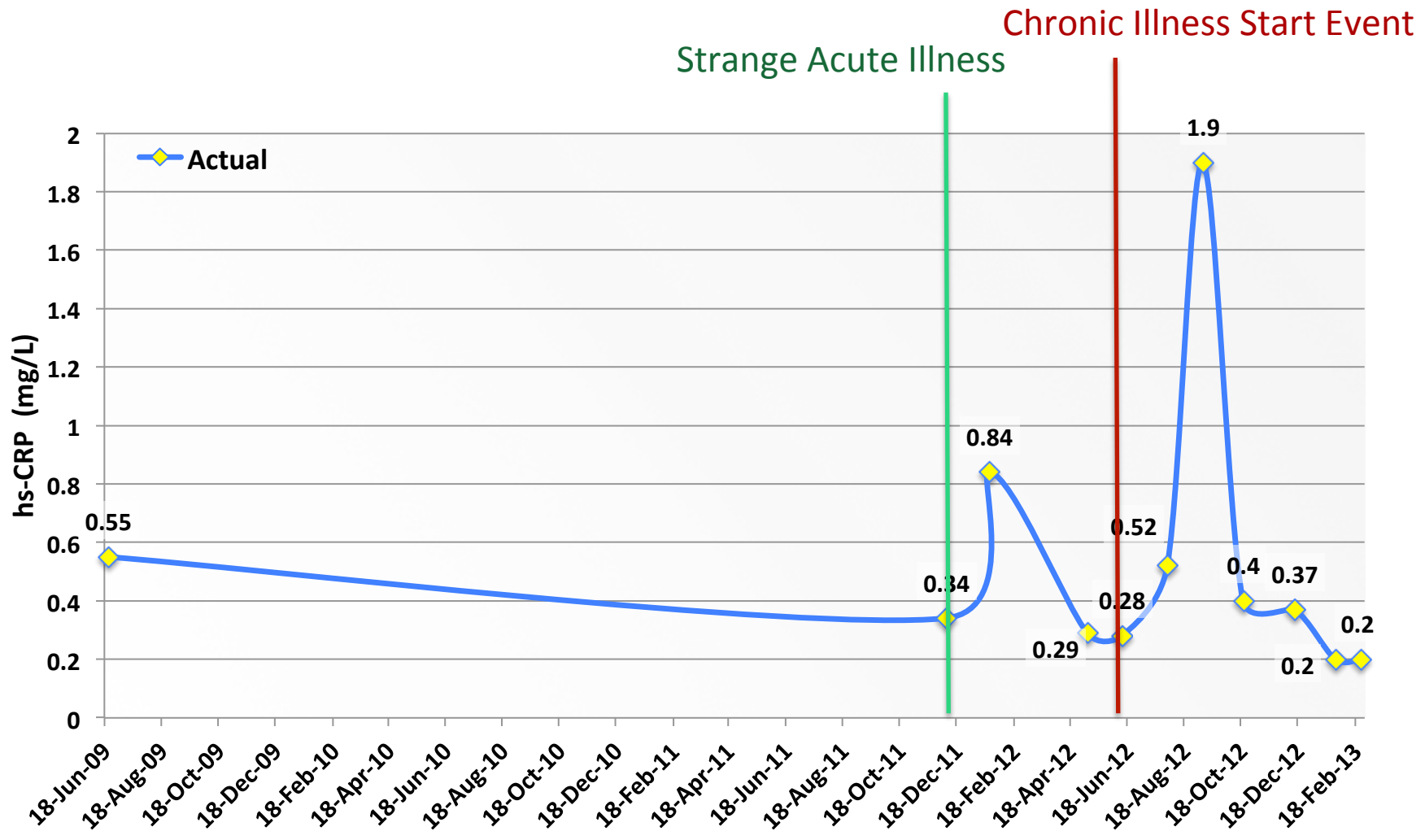
# Approach #1: “Conventional Route”

## Conventional Data Collection

- No Abnormalities
  - EEG (ElectroEncephaloGraphy)
  - MRI (Magnetic Resonance Imaging)
  - CT Scan (Computed Tomography)
- Minor abnormalities within ‘normal reference range’
  - CBC (Complete Blood Count)
  - Liver Function
  - Lipids
  - hs-CRP

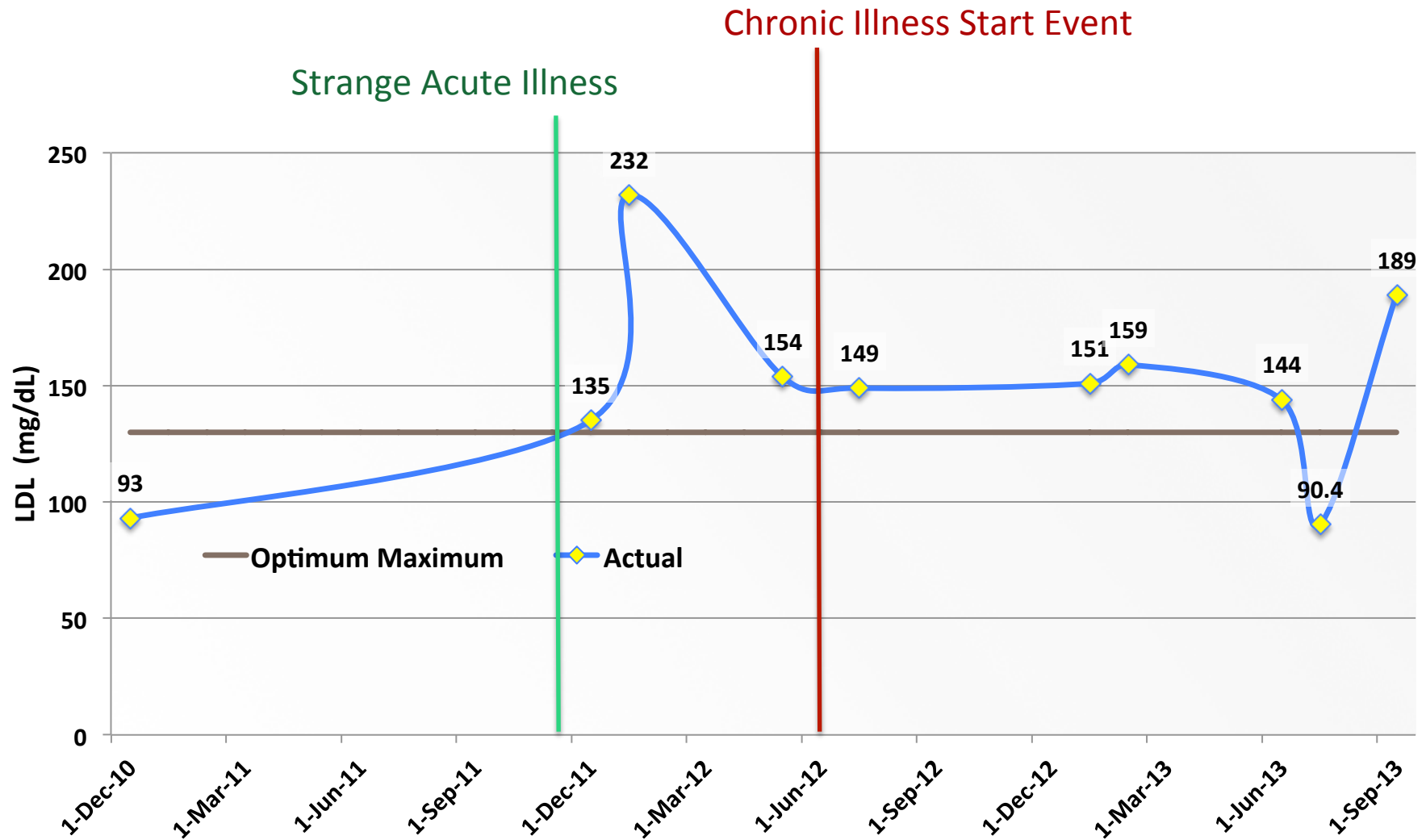
# Approach #1: Conventional Route"

## hs-CRP Inflammation Acute + Chronic Spikes



# Approach #1: “The Conventional Route”

## LDL Infection Acute Spike



# Approach #1: “Conventional Route”

## Takeaways

- **Problems:** No progress with Conventional medicine
  - Non-acute illness = Labs in “normal reference range”
  - Doesn’t fit “conventional templates” for illness
- **Progress:** Baseline labs prior to sickness
  - Showed ‘unhealthy change’
  - Some kind of infection? (*LDL, CRP spikes*)



# Approach #2: “Track Everything”

## Data Collection

### Labs

- Heavy Metals (Doctor’s Data)
- Vitamin D
- Genetics (23andMe)
- Micronutrient deficiencies (Spectracell)
- EFA (Essential Fatty Acids)
- Iron/ Ferritin Load
- Homocysteine
- Gut environment (Metametrix)

### Self Tracking

- Symptoms
- Blood sugar monitor
- Sleep duration
- Stool frequency/ consistency
- Food intake
- Supplement intake

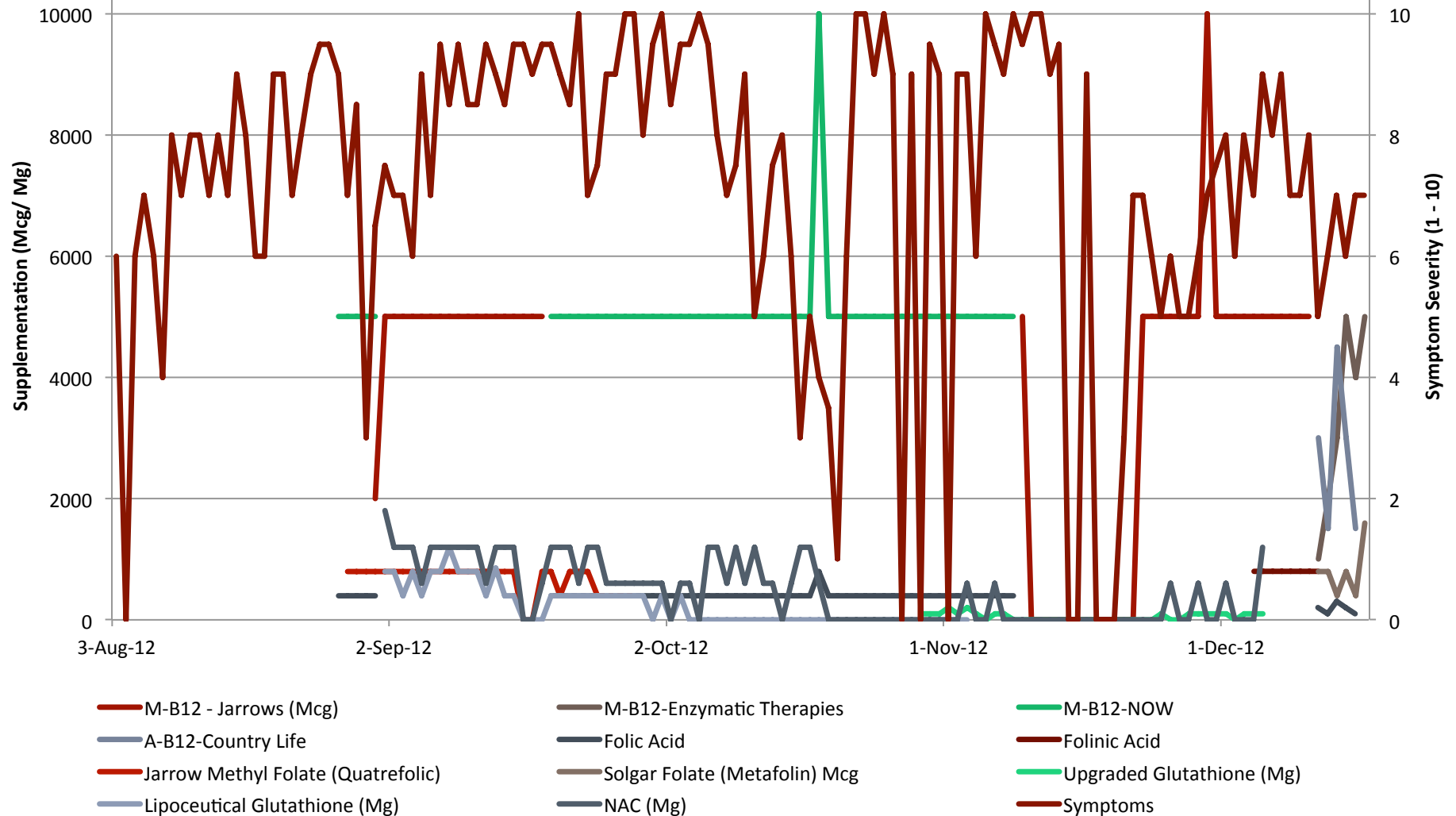


*awesome data tracking app*

**Lumen Trails iPhone App**  
[www.lumentrails.com](http://www.lumentrails.com)

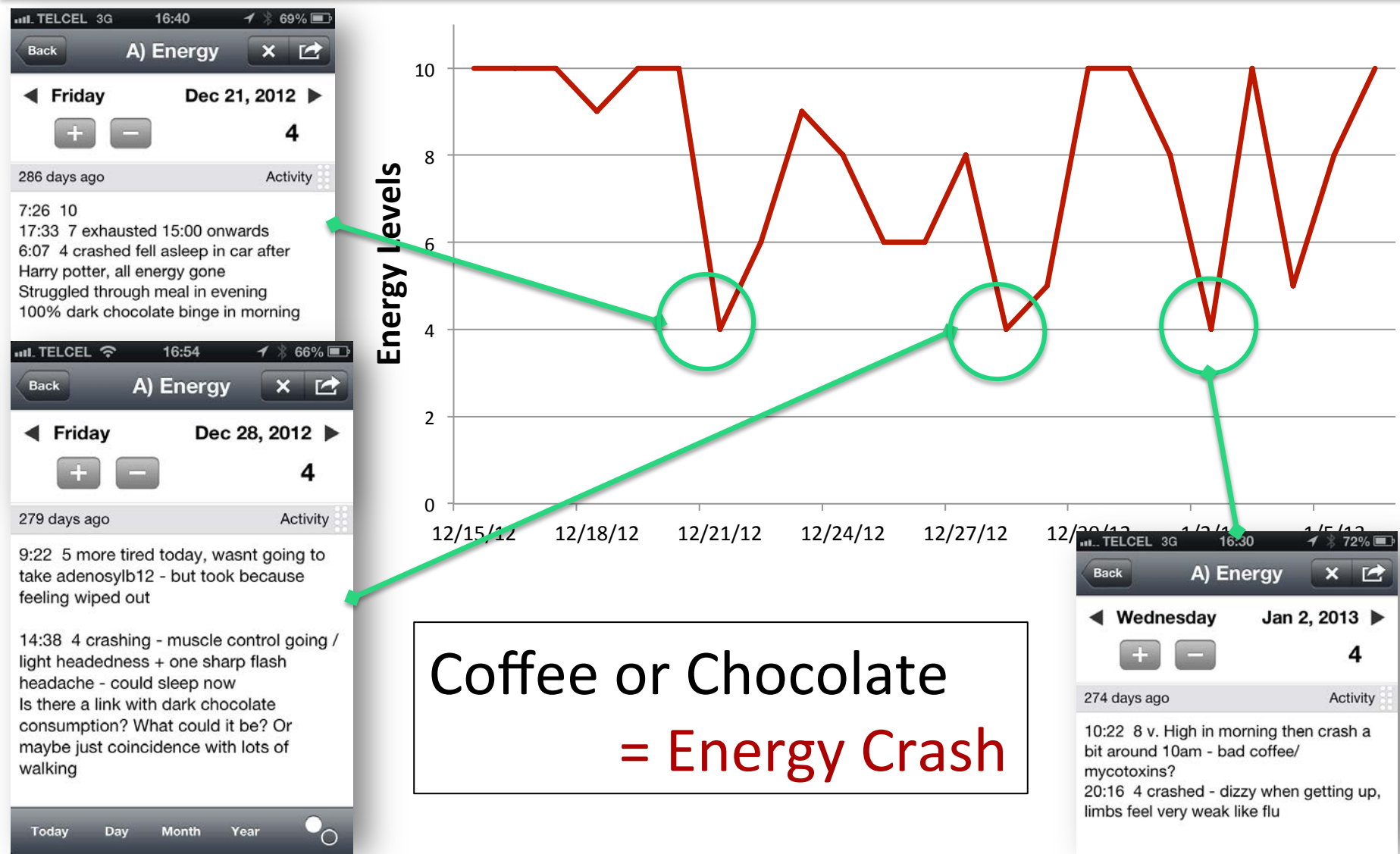
# Approach #2: "Track Everything"

Quantifying Symptoms + Factors = Confusing Mess



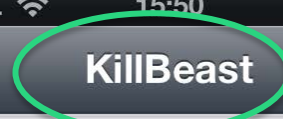
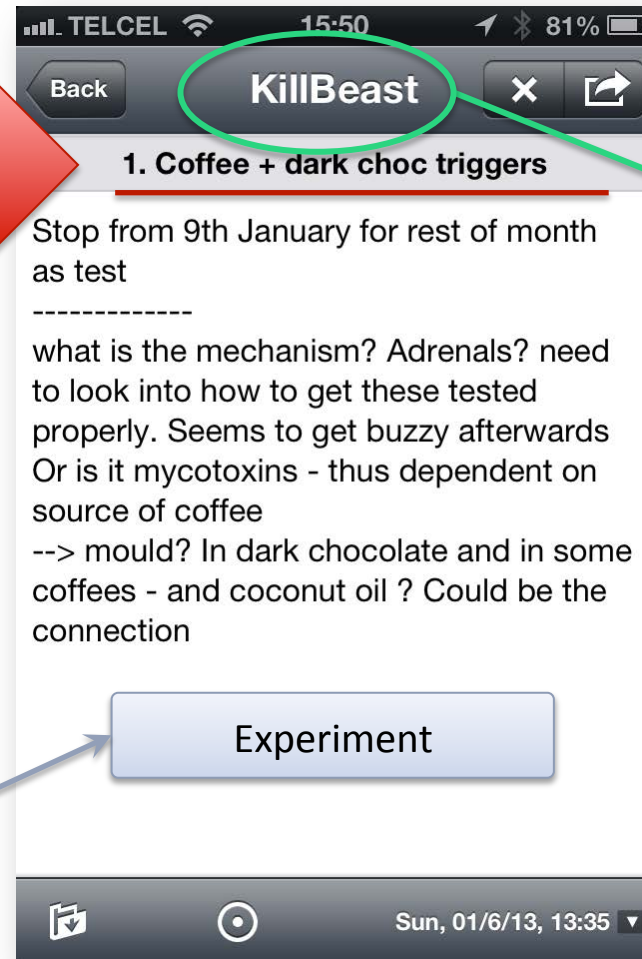
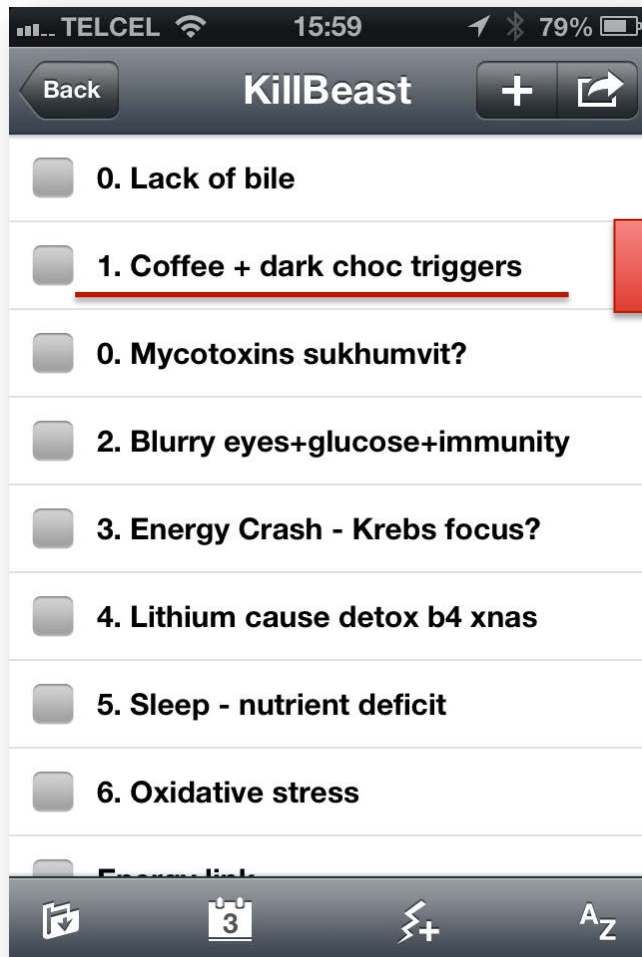
# Approach #2: "Track Everything"

Journal Factors + Quantify 1 Symptom = Insight



# Approach #2: "Track Everything"

## Elimination Experiment to Prove



Pet name  
given to  
illness  
project

Experiment

Hypotheses

# Approach #2: “Track Everything”

## Takeaways

- **Progress:** ‘Specific’ avoidance helps manage symptoms
  - **Gluten, Casein** = Gut Issues
  - **Chocolate** and **Coffee** = Energy crashes
  - Are these clues?
- **Problems:**
  - No closer to a ‘diagnosed illness’ progress
  - How can I work smarter?

# Approach #3: Find “Uniqueness”

## Nervous System and “Trembling”





# Approach #3: Find “Uniqueness”

## Data Collected

- Lab Test
  - Epstein Barr Virus antibodies (**raised**)
- Experiment
  - 1 week on psychoactive drug **Deanxit** to link to sympathetic nervous system activation
  - (**Stopped the trembling**)

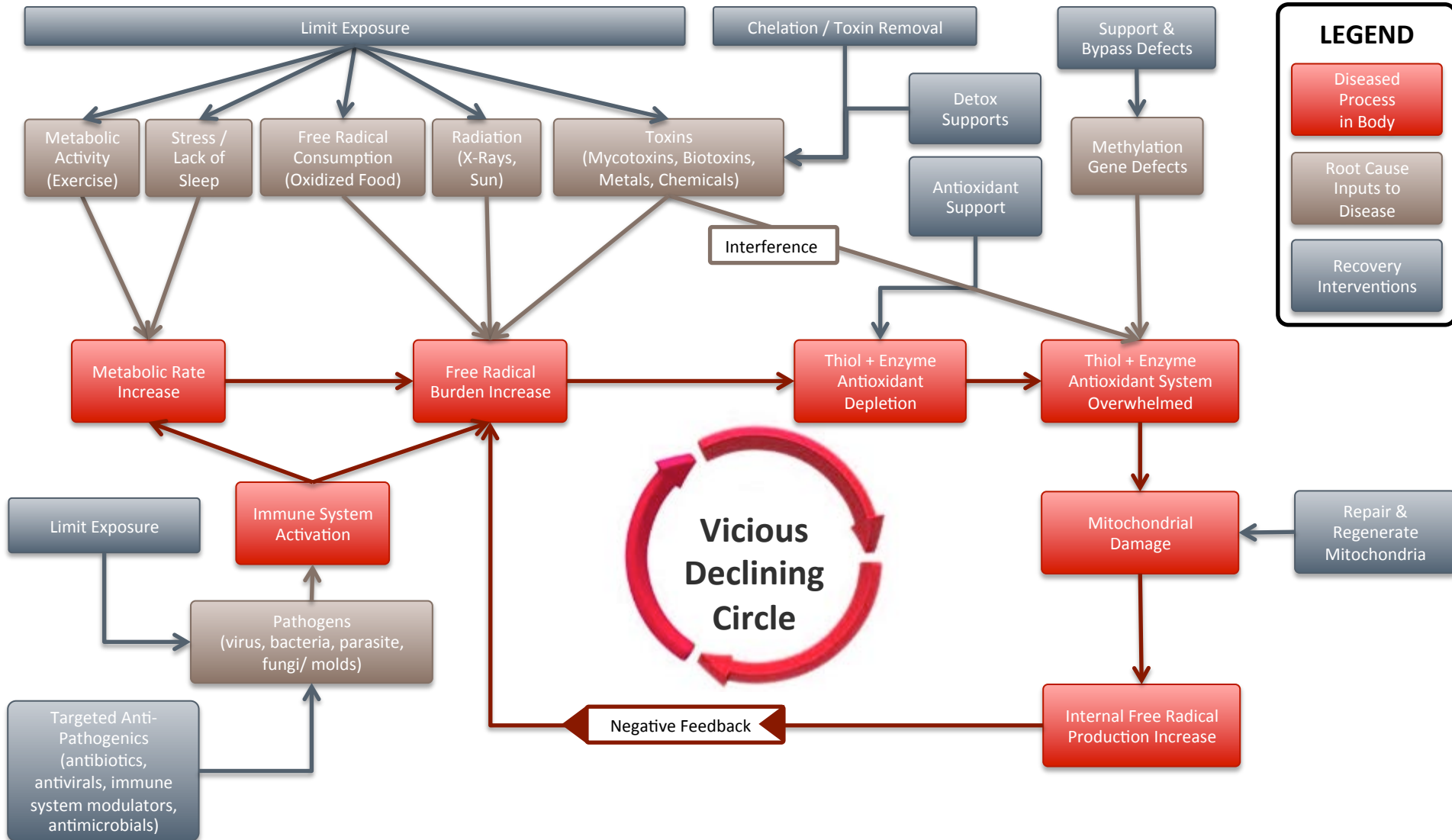
# Approach #3: Find “Uniqueness”

## Takeaways

- **Progress:**
  - Got a diagnosis “Chronic Fatigue Syndrome (CFS)”
- **Problems:**
  - CFS is not a differential diagnosis. Groups people loosely with similar symptoms and very rough biomarkers.
  - CFS is an incurable and progressive illness.

# Approach #4: "Attack Everything!"

## After Lots of Reading...



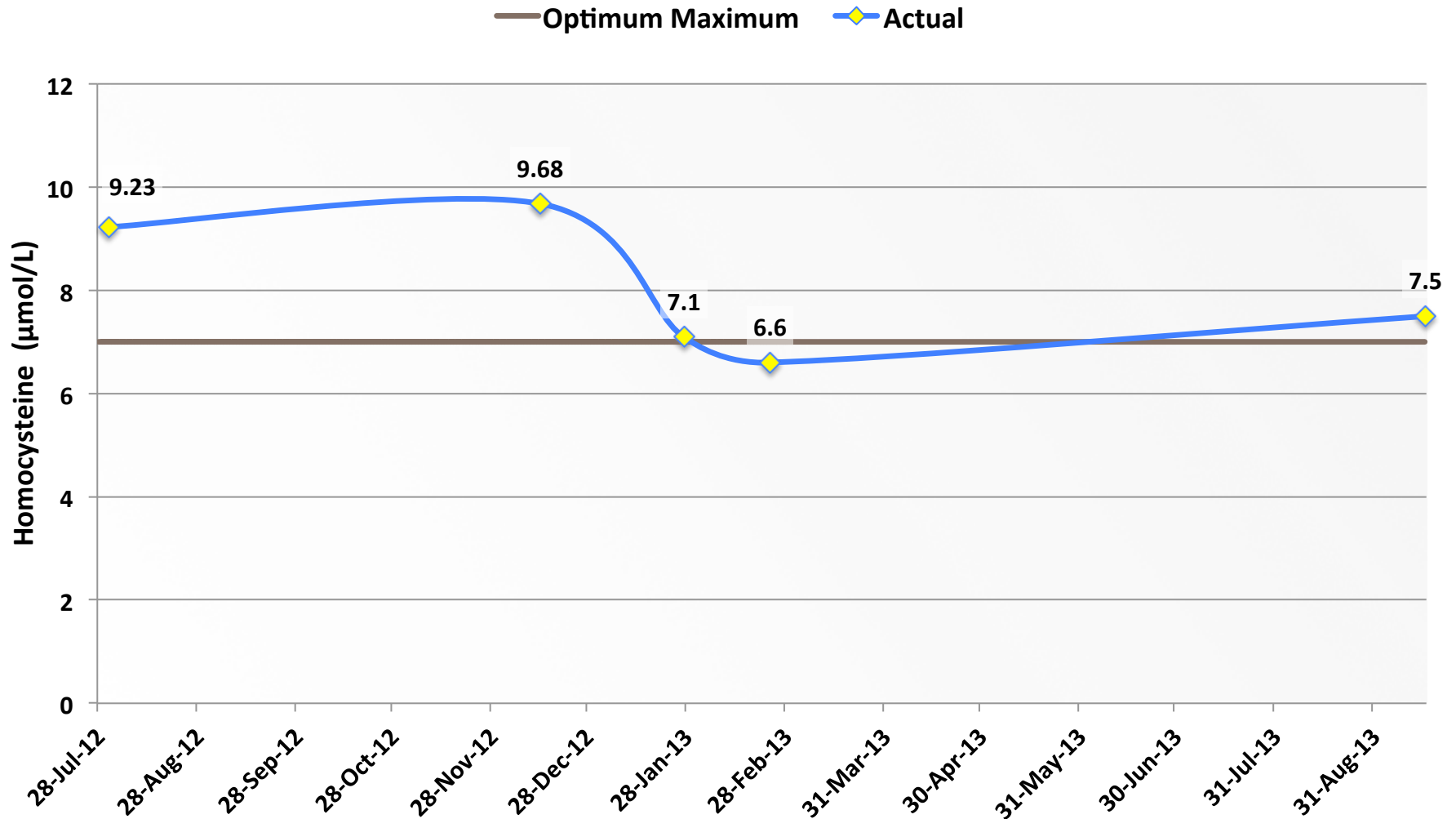
# Approach #4: “Attack Everything!”

## Data Collection

- **Blood Labs**
  - Methylation profile and genetics (low methylation/ glutathione, high oxidation, low detox function)
  - Mitochondrial profile (low mitochondrial function, high DNA damage)
- **Urine Labs - substrates**
  - Urine Amino Acids (high ammonia)
  - Essential Elements (low potassium)
- **Pathogens/ Toxic burden**
  - Stool test (Blastocyst hominis, helicobacter pylori positive)
  - Heavy metals urine and hair tests (high arsenic, mercury, uranium, cesium)
- **Biometrics via Tracking Devices**
  - MyBasis watch - perspiration, heart rate, sleep (night sweats, short sleep duration)
  - HRV monitors - emwave2, chest strap + HRV sense (low HRV, high stress, sympathetic activation, heart rate jump on exertion)

# Approach #4: “Attack Everything!”

## Homocysteine



# Approach #4: “Attack Everything!”

## Takeaways

- **Progress**

- Lots of “out of normal reference range” data
- Clear methylation and mitochondria damage
- Managing condition now – not getting worse.
- ***Silverlining:*** Discovered many other health issues



# Approach #4: “Attack Everything!”

## Takeaways

- **Problems**

- ***High investment, low return:*** Lots of time and effort to make little progress.
- ***No Clear Cause:*** No clear cut hypotheses for cause of illness supported by data.
- ***Not likely to cure:*** Some people go into remission through symptoms management, but not cured.

# Approach #5: Find “Big Data”

Who aggregates and analyzes lots of data?

- **Methylation and CFS >> Dr. Amy Yasko**
  - All patients reporting back data monthly
  - Wide variety of tests
  - Analyzes aggregate data by genetic fingerprint
  - Adjusts hypotheses and protocols on ongoing basis

# Approach #5: Find “Big Data”

## Critical Mass of Insights: The “Mold” Connection

- Dave Asprey’s blog
  - Coffee + chocolate often contain “Mycotoxins”
  - Mycotoxins are toxin secreted by Mold
- Unique symptoms
  - Coffee + Chocolate = Energy crash
- Flashback: I stayed in a house with visible mold in 2011

# Approach #5: Find “Big Data”

Who aggregates and analyzes lots of data?

- “Mold” and Biotoxin Illnesses
  - Dr. Ritchie Shoemaker
  - 16 years of data and published studies
  - Clear recovery protocol for “Cure”

# Approach #5: Find “Big Data”

## Data Collection

- **Dr. Ritchie Shoemaker – “Biotoxin Illness”**
  - **Screening:** Visual Contrast Sensitivity, Symptoms Clusters
  - **Specific Genetics:** HLA - Human Leukocyte Antigens (Mold susceptible, post-lyme susceptible)
  - **Specialized labs:** Innate immune system inflammation markers (C4a, C3a, TGF-Beta 1) and many other markers of differential damage

# Approach #5: Find “Big Data”

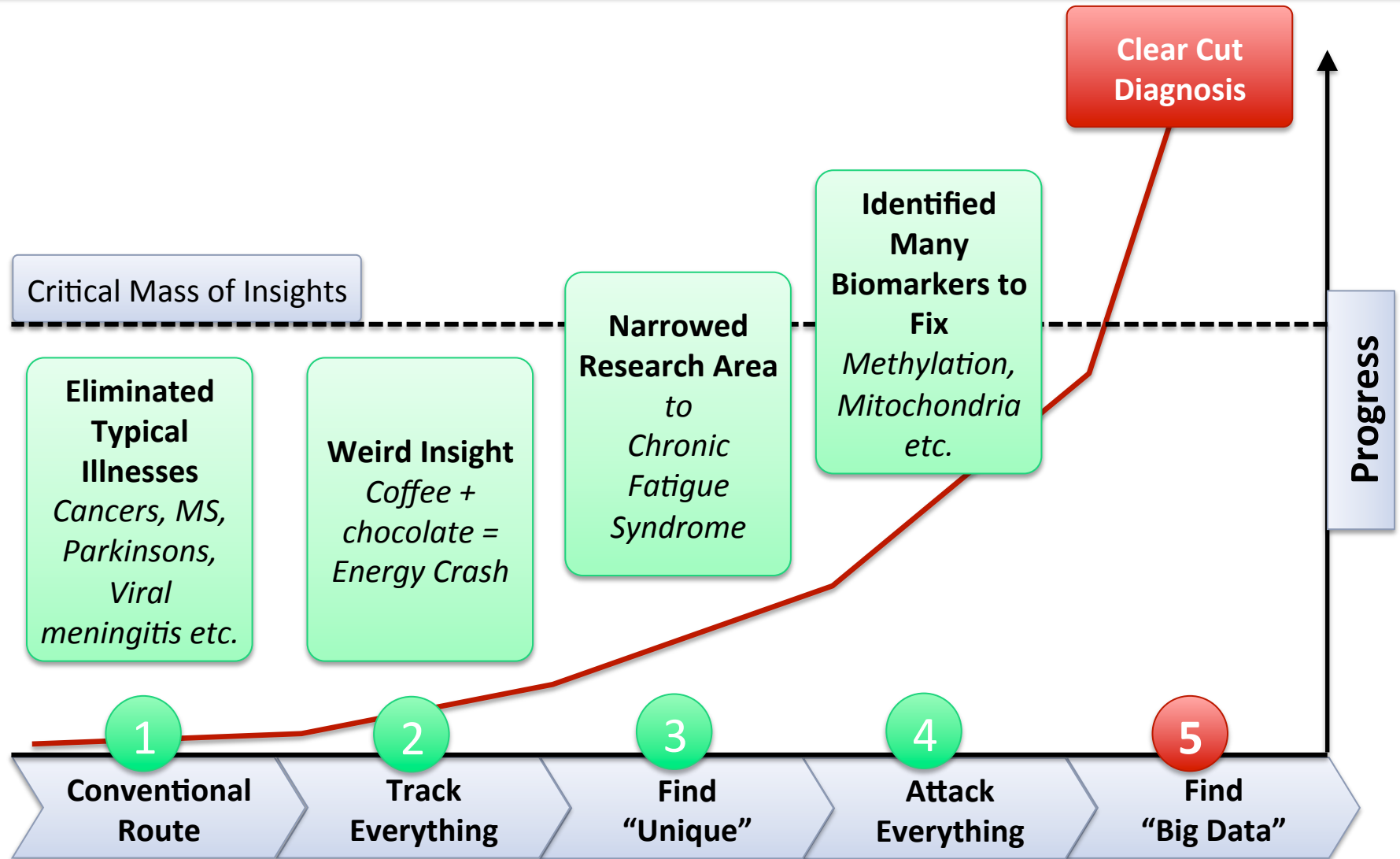
## Takeaways

- **“Winning!” – Clear diagnosis for Biotoxin Illness**
  - Symptoms cluster **positive**: statistical significance
  - Visual Contrast Sensitivity **positive**: > 50% below controls
  - Genetic fingerprints **positive**: Both biotoxin and methylation defect susceptible
  - Lab fingerprints **positive**: Specific inflammation present



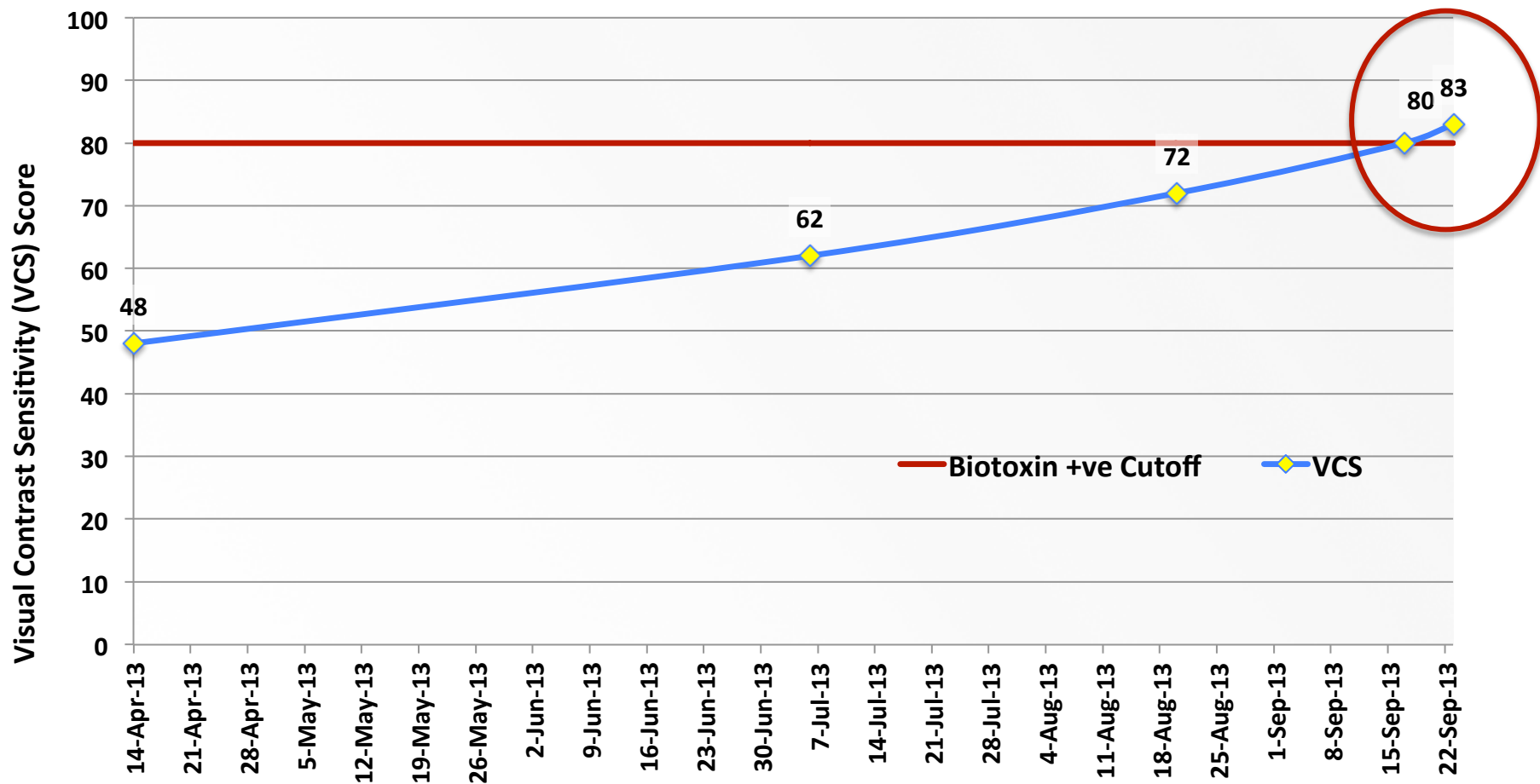
# Conclusion

Each Approach Pushed the Journey On...



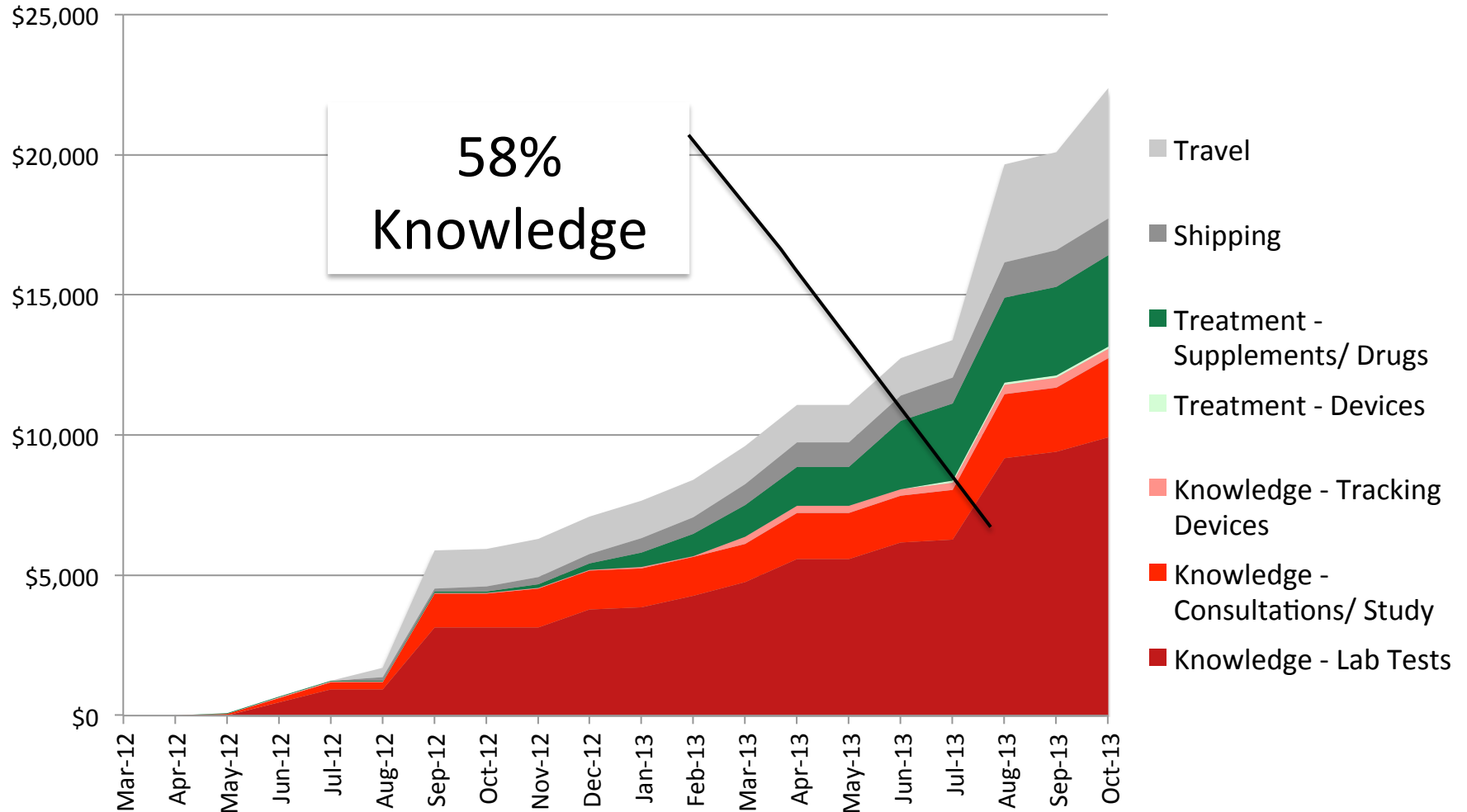
# Conclusion

## VCS - Progress w/ Treatment Since Diagnosis



# Conclusion

## How Much Did this Cost So Far?



# Aftermath

## Diagnosis Done... Recovery in Progress...

- Every confusing symptom *Explained*
- Every data point *Explained*

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