

# Time line of events of VA RAC over 20 years

Gulf War Illness over view?

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# Creation

- Product of 1998 Omnibus bill that gutted the language, as it was cut down each time it was reintroduced
- Signed into law in Nov 11 1998
- Launch in April 11th 2002
- First year would be data collection and setting methodology to its 2004 report

# The Golden Years

- Given the tenderness of the situation, the committee was allowed to self govern.
- It broke rank with tradition and took on subjects the audience demanded
- It published statements that made VA uncomfortable including healthcare and benefits.
- They challenged DOD reports and dogma

# Research?

- Up to 2005 the RAC tried to deal with the government word play over presumption of illness to open treatment doors
- PON q, Anthrax Vaccine, CoQ10, PB tabs, birth defects, and such took center stage.
- Participated in numerous congressional hearings and inquiries with Government Reform.
- Brought in European counter parts to these hearings.
- They took point in getting a biorepository after the glowing failure of the AFIP to be cooperative
- Took charge to create the CDMRP funding for more research rather than just DOD

# Grand gesture

- Knowing the committee was over loaded with its CDMRP task, it needed help
- 2007 it published the need to separate task with a healthcare benefits committee
- It endorsed the formation, and saw its creation by VA Sec executive privilege
- Was distracted by numerous biased IOM reports contracted by VA

# When Undefined became CMI-UDX

- After 2005 the focus was divided between PonQ neurology and metabolic features
- Terminology changed away from undiagnosed illness conditions – undefined would become a catch all for not looking for tissue evidence
- Sample collecting was mostly standard blood labs, and then came the molecular shift about proteins
- Self reporting is the basis of Registry programs not supplying tissue samples to pool data from
- So the push becomes multi chronic illness

# The IOM contract failures

- Attending IOM reports being contracted became a sore point, as the NAS used contract verbiage to limit the scope of studies to peer review literature only
- This led to the shift in the ALS study from Gulf War vets to all deployments, and the deployment health became the new basis - diffusion
- VA now argued with the RAC to follow this model, take the word “Research” literally
- The RAC shifted its membership and resources to the CDMRP to break with restrictions imposed

# The great contraction

- By 2009 VA set out to change research with the PDICI, WRIISC, and deployment health
- The Gulf War Illness Task Force met during 2010 in secret that year to take away from the RAC – further alienate them from VA
- Was distracted by numerous biased IOM reports contracted by VA, the worst being the ALS study
- With the closing of the VA ACGWV committee in 2009, external veteran involvement with VA was cut off other than RAC public comments



# Millennium Cohort, and WRIISC

- In 2010 VA was making all out effort to funnel Gulf War through its deployment health ranks, and studies by VA
- Millennium Cohort, and WRIISC studies were the energy would be put.
- IOM stopped including grass roots in its meetings and reports
- Registries and programs were forgotten

# OIF, and Burn Pits

- VA was focused more on OIF, and the issues beginning to surface in 2004.
- Gulf war was now low key enough VA could focus on decimating the RAC.
- It stopped public mortality reporting system, and then service connection reports
- Neurology and Neuroendocrine had begun to be taken more serious

# Burn Pits take over

- 2013 to 2014 would be the implementation of Burn Pit registry
- Then VA sets out for 8 years to make ABHOR non-tissue collecting even with Gulf war vets – only 9% even get exams.
- Silicosis is still not taken serious with this

# The dark years

- Sec of VA Eric Shinseki having rid himself of the disruptive RAC members, VA largely silences the RAC from 2012 on...
- No more opposition reports, healthcare and benefits comments. No more hearings and shocking public statements
- Multiple chairmen come and go towing the VA line, even trying to run off vets in circular arguments or research word play
- Most of what is found in Gulf war medicine is repetitive and does little to change things

# COVID years

- Registry programs, WRIISC, IOM, and others research scenarios grind to stagnation
- 2018 is the last gulf War hearing, and it focuses too much on the CDMRP
- End of 2019, public VA shuts down. April 2020 is the year of total isolation
- VA has the new tool of hiding from people via virtual meetings, ignore people in plain sight
- Physical tissue collection of any kind mostly shuts down in VA, cant get in to do it.

# 2022 - Darkest year of all

- 30<sup>th</sup> anniversary of the Gulf war is glossed over, happens silently
- The RAC now is in total servitude to VA and completely indifferent to the public
- For a year its lip service, total indifference
- But, in the background the PACT act comes and passes congress
- The cancer clusters are implied

# The PACT act and ABHOR

- NAS study concludes the Burn pit registry system does not function, this includes 8 years of missing Gulf War medical data
- PACT act demands GWI involvement and new respiratory, pulmonary data
- ABHOR becomes the new data source under the PACT act for WRIISC and Gulf war registry exams

# Data collection as of 2022

- Even though the HOME database is consolidated from multiple sources, its still dependent on crude collection methods.
- 90% is survey and self reporting.
- Blood labs and images are traditional
- Tissue collection is largely surgery biopsies
- External sources outside of VA are done through back door of SS billing records



# The Two main research aspects?

- There are two main areas of concern that can lead to answers.
- Total genomic function or alteration.
- Residual compounds stored in body tissues.

# Not doing the autopsy “post mortum”

VA is very touchy when it come to invasive procedure.  
They just dont do them.

The shift should be thinking like a corner and use that narrow window to find out everything you can that day

That taking adipose fatty tissue is a snap shot that would provide hard evidence of anything in parts per billionth. Such as DDT from our childhood much less current insults. You know thats real, maybe its a factor too. Additive.

# Total genome debate

VA treats the genome as too big to look at. So it hinges on mostly studying hand picked items in the genome related to substance abuse and such

Its time to look at the whole genome, and what changed versus general public.

Sequencing is cheap, analysis is getting there. Time to put AI to work.

# Enzymatic errors

There are thousands of proteins and enzymes at play here. But, more and more it looks like Hypo-function is the issue.

Metabolism function has slowed, enzymes are low or inhibited. 10% to 15% or more. Subtle variations.

VA needs to stop the “wait till is terminal” approach and realize Gulf war metabolism and organ health are in the subtle low end on the way to critical. You cant keep waiting for blood labs to go critical.

The buzz word had been Cholinesterase inhibitor, its not just the one enzyme and its systemic –  
Lisosome Function?

# Long Covid - POTS

## Post Orthostatic Tachycardia Syndrome

May very well be a new feature in our ranks and explain my last year of new problems with the Vagas nerve.

The aspects of Covid should make it presumptive while finding answers because it prays on our very weaknesses. Those like me with long Covid has this to deal with.

# The cancer clusters and public reporting

We cant just leave the VABBB to surgery tissue samples.

There has to be a way to expand tissue collection to living tissues such as fatty tissue sections, bone, hair, nails

We need a public catalog by category that researches can pick from.

We need monthly public reporting systems to follow living, and morbidity results of Gulf war vets health

# The RAC in 2023?

The RAC of the first 10 years understood outreach, it tried to bridge the gap from Research to **Services and Benefits**. Because the committee itself was intended as a service to the veterans. VA forgot this in 2014, and saw the committee as a tool to stall veterans diagnosis, and possible treatment. It forgot that PL 105-368 says this in section 104 subsection E. Which it even removed from the VA RAC website

“(e) OUTREACH.—The head of the department or agency designated under subsection (a) shall ensure that the appropriate departments consult and coordinate in carrying out an ongoing program to **provide information to those who served in the Southwest Asia theater of operations during the Persian Gulf War** relating to:

**(1) the health risks, if any, resulting from any risk factors associated with such service; and (2) any services or benefits available with respect to such health risks.”.**

# The End?

Right now OIF and others have broken ranks. You can follow VA and be unremarkable in the face of that, or be a real part of it.

You will have to oppose VA Policy and Planning as well as ORD to do it. United.

Think outside the box. Its not just words. The last decade is proof VA's Eric Shinseki vision was short sighted and questionable.