



vh2025



Real People, Real Action, Real Results:
**Bringing the Hepatitis B
Affected Community Voice to the Table**

Su Wang, MD MPH

Medical Director, Viral Hepatitis Programs & Center for Asian Health
Cooperman Barnabas Medical Center, New Jersey, US
Assistant Professor, **RWJ-Rutgers Medical School**

Senior Advisor, Global Health, **Hepatitis B Foundation**
NOhep Medical Visionaries Ambassador
Past-President, **World Hepatitis Alliance**

15th Australasian Viral Hepatitis Conference
August 6, 2025



Disclosures

Grant:

Gilead Sciences- FOCUS screening/linkage to care (funding to institution)

Flashback from 6 years ago



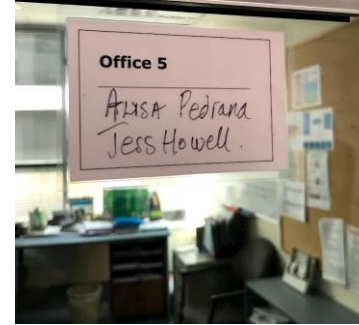
AVHEC 2019

Conference Handbook

2nd Australasian Viral Hepatitis Elimination Conference

5 - 6 August 2019
Novotel Sydney Brighton Beach Hotel

#AVHEC19 

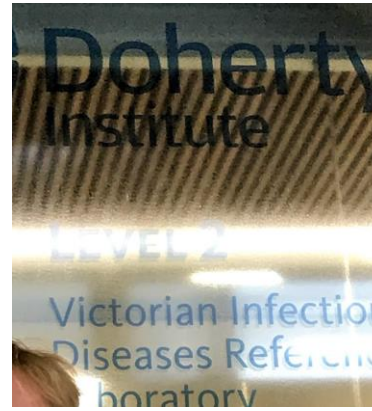


AVHEC 2019

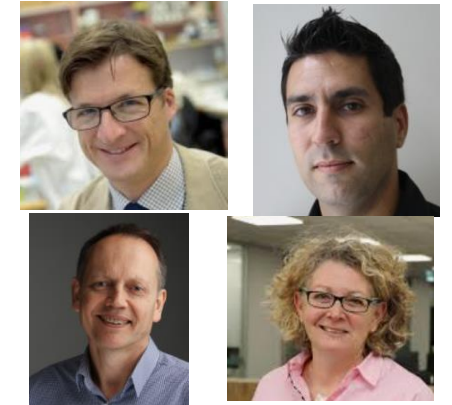
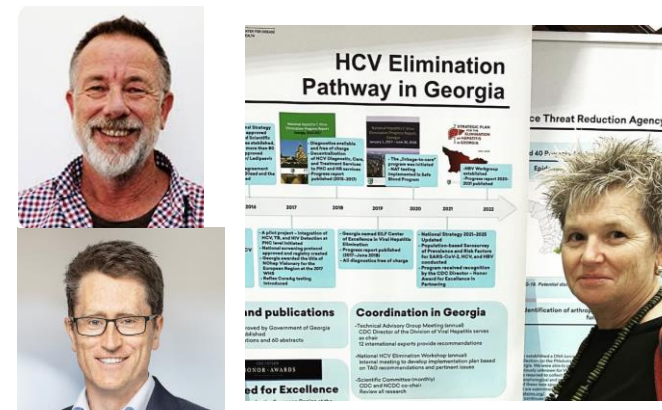
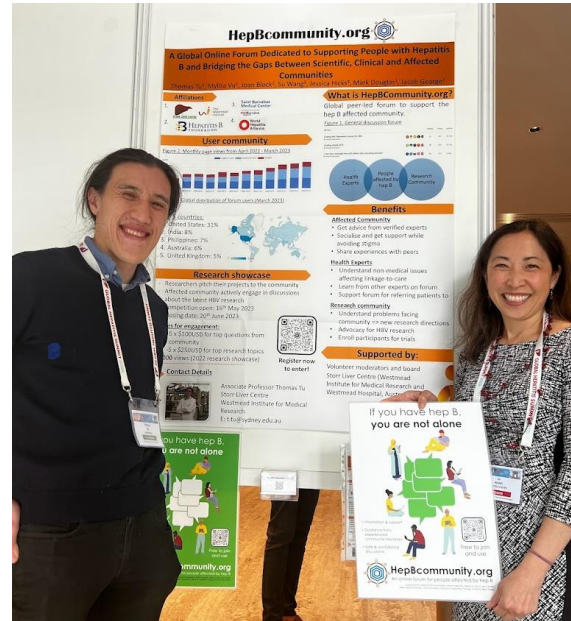
Nate Chen
Companion

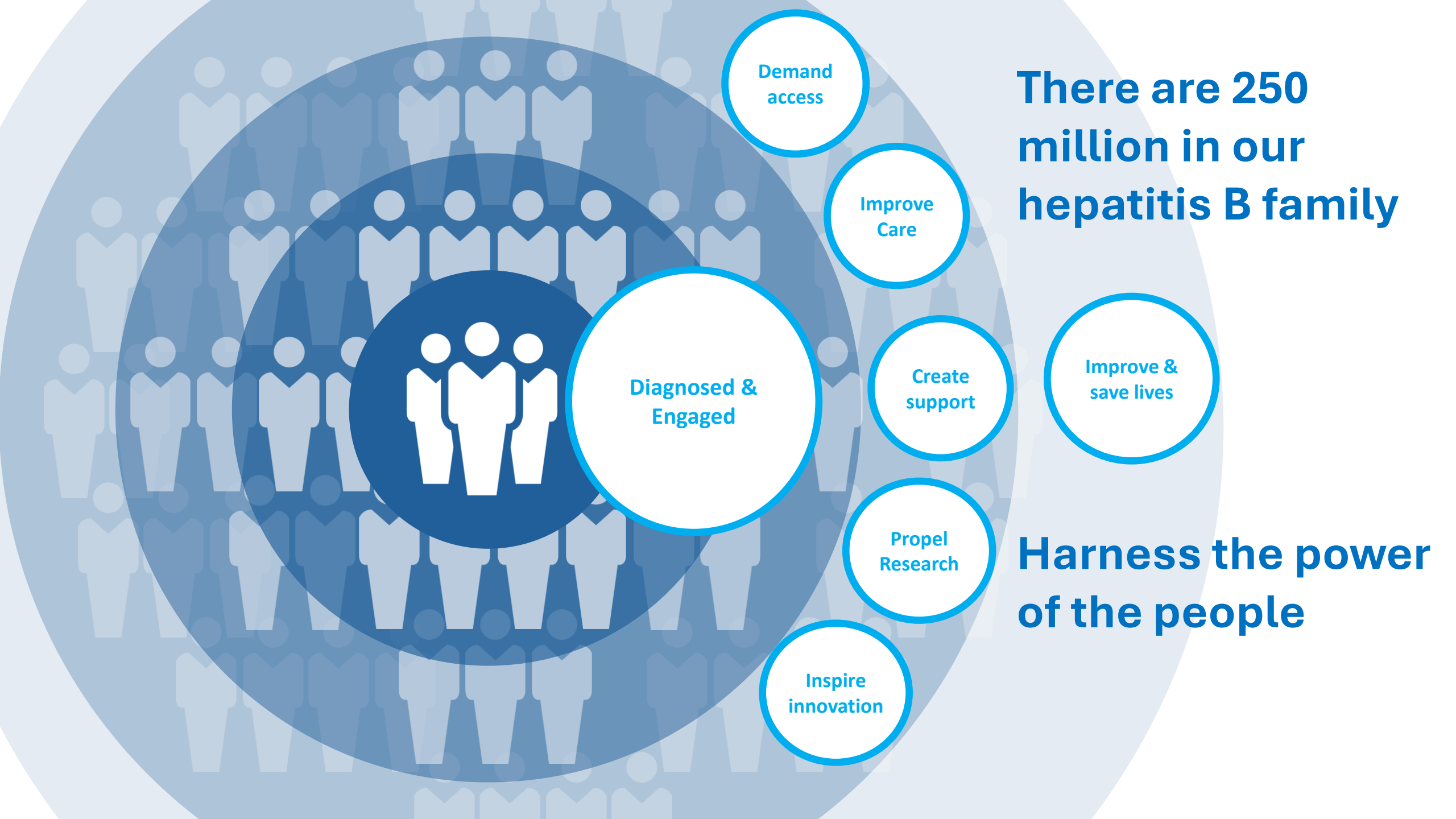


SESSION ONLY



Australian HBV influences on my journey





Demand
access

Improve
Care

Create
support

Propel
Research

Inspire
innovation

Diagnosed &
Engaged

**There are 250
million in our
hepatitis B family**

Improve &
save lives

**Harness the power
of the people**



Lien Tran
Australia/Vietnam



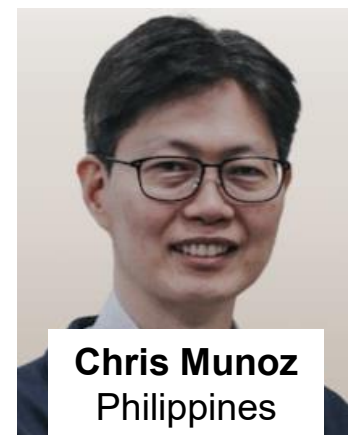
Nafisa Yussf
Australia/Somalia



Thomas Tu
Australia



Danjuma Adda
Nigeria



Chris Munoz
Philippines

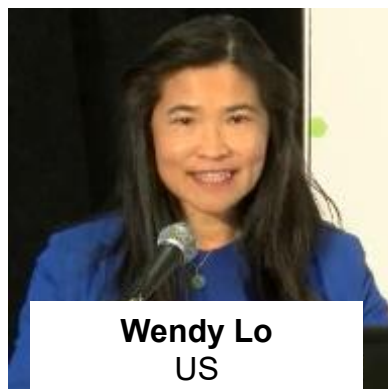


Dee Lee
China

These are my amazing hepatitis B brothers & sisters



Shaibu Issa
Tanzania



Wendy Lo
US



Jacki Chen
US/Taiwan



**Theobald
Owusu-Ansah** Ghana



Silvana Lesidrenska
Bulgaria



Ravshan Yakubov
Canada/Uzbekistan



Bright Ansah
US/Ghana



Joan Block
US



Supa Chantschool
UK/Thailand



Kenneth Kabagambe
Uganda



Joe Balestreri
US

Amplifying stories and building communities



Welcome to the Hepatitis B Foundation's storytelling website, where we share genuine stories from real people living with hepatitis B worldwide.



If you have hep B,
you are not alone

- Information & support
- Guidance from experienced community members
- Safe & confidential

Free registration

HepBcommunity.org
An online forum for people affected by hep B

Supported by Hepatitis B Foundation, World Hepatitis Alliance, Star Liver Centre (Westmead Hospital), and Australian Centre for Hepatitis Virology. Artwork: Becci Orpin



Hep B Story

A visual, interactive app which is designed for patients living with chronic hepatitis B and their families

11 Aboriginal languages available now

Yolju Anindilyakwa Arrernte Burarra
Kriol Pitjantjatjara Tiwi Warlpiri Kunwinjku
NEW Murrinh Patha Wubuy

GET IT ON Google Play Download on the App Store

menzies
SCHOOL OF HEALTH RESEARCH


World Hepatitis Alliance

Our mission

Harness the power of people living with viral hepatitis to achieve its elimination



Best practices for engaging with affected communities: chronic hepatitis B as a case study

Thomas Tu^{1,2,3,4,5,6*} , Nafisa Yussf⁴, Lien Tran^{4,5}, Kim Ngo⁴, Su Wang^{5,7}, Adi Mondel⁸, Isabelle Purcell⁸, Jacki Chen^{5,9,10}, Wendy Lo⁵, Bright Ansah⁵, Kenneth Kabagambe^{5,11}, Soumen Basu^{5,12}, Dee Lee^{6,13}, Supa Chantschool¹⁴, Chris Munoz^{5,15}, Ivana Dragojevic¹⁶, Marko Korenjak¹⁶, Fiona Borondy-Jenkins⁵, Yasmin Ibrahim⁵, Beatrice Zovich⁵ and Chari Cohen⁵

Principles

Collaborate with community partners early and throughout the project design, providing opportunities for actionable input into the process

Remunerate community partners appropriately for their expertise

Invite more than one community partner

Recruit community partners through established community groups

Provide contract agreements that are easy to understand and equitable

Choose the right level of engagement

Ensure accessibility of briefing information ahead of meeting

Recognise the technical support needed to optimally engage

Be mindful of community partners during a meeting, actively seek out their counsel, and engage with them

Ensure safety and respect boundaries regarding confidentiality, privacy, and disclosure

Use trauma-informed practices and practice cultural safety

Provide emotional support to community partners

Debrief with community partners and include them in follow-up steps



We are in a storm of disruption & upheaval

Thousands Laid off From NIH, FDA and CDC After Supreme Court Decision

By HealthDay | July 16, 2025, at 10:30 a.m.

RFK Jr.'s New Vaccine Panel Casts Doubt on Hepatitis B Shot at Birth

By Jessica McDonald and Kate Yandell

Posted on June 26, 2025

'A bloodbath': HIV field is reeling after billions in U.S. funding are axed


USAID's promises to support lifesaving efforts are broken, putting millions in peril

Trump administration to cut all USAID overseas roles in dramatic restructuring

State department to take over US foreign assistance programs as staffers warn of devastating impact

CORRESPONDENCE · Online first, February 06, 2025

Pathogens don't respect politicians: US federal disruption poses a new threat to global public health

[Su Wang](#)^a · [Mark Harrington](#)^b · [Camilla S Graham](#)^c · [Louise O Downs](#)^{d,e} · [Nancy Kagwanja](#)^e · [Anthony O Etyang](#)^e · [Collins Iwuji](#)^{f,g} · [Thumbi Ndung'u](#)^{g,h,i,j} · [Benjamin C Cowie](#)^k · [Kenneth Kabagambe](#)^l · [Philippa C Matthews](#)^{h,m,n} 

[Show less](#)

[Affiliations & Notes](#)  [Article Info](#) 

We are facing a new threat to global health.

The COVID-19 pandemic made it clear to health-care providers, public health practitioners, policy makers, and communities that pathogens do not respect borders.¹ Now we highlight that nor do infectious diseases defer to presidents or politicians. Changes imposed by the new US administration in January, 2025, rapidly began to dismantle a complex global ecosystem of public health strategies and institutions that have been established over the past century to protect communities from infection and other public health threats.

Trump's Budget Calls for Deep Cuts to Public Health Programs and Research

A budget blueprint released on Friday advances, in hard numbers and biting words, President Trump's assault on the nation's universities and scientific research enterprise.


Proposed Reorganization of US Health and Human Services

- **Personnel cuts, centralization of functions, consolidation of HHS divisions:**
 - 82,000 full-time employees to 62,000
 - 28 divisions consolidated to 15
 - 10 regional offices to 5
 - Centralization of HR, IT, Procurement, External Affairs and Policy
- **FDA, CDC, NIH, CMS (Medicare/Medicaid) workforce reductions:**
 - **FDA** by 3,500; “focus on streamlining operations and centralizing administrative functions”
 - **CDC** by 2,400; “focus on returning to its core mission of preparing for and responding to epidemics and outbreaks”
 - **NIH** by 1,200; “centralizing procurement, human resources, and communications” across 27 institutes/centers
 - **CMS** by 300; “focus on reducing minor duplication across the agency”
- **New Administration for a Healthy America (AHA)**
 - Consolidates OASH, HRSA, SAMHSA, ATSDR, NIOSH
- **Other:** ASPE to be combined with AHRQ into Office of Strategy; Administration for Community Living split across ACF, ASPE, CMS

What is the role of community during stormy times?

A tale about a thunderstorm in New Jersey

Monday July 14: Thunderstorms and flash flooding in New Jersey


Emergency Alert
National Weather Service: A FLASH FLOOD WARNING is in effect for this area until 9:45 PM EDT. This is a dangerous and life-threatening situation. Do not attempt to travel unless you are fleeing an area subject to flooding or under an evacuation order.

Additional Details
Turn around...don't drown when encountering flooded roads. Most flood deaths occur in vehicles.
Move to higher ground now. Act quickly to protect your life.
Be aware of your surroundings and do not drive on flooded roads.
Please report observed flooding to local emergency services or law enforcement and request they pass this information to the National Weather Service when you can do so safely.

Emergency Alerts Show less

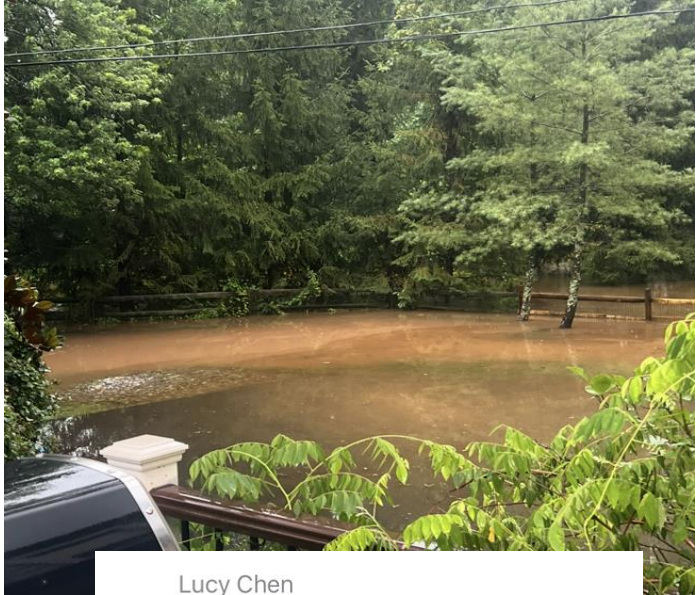
Emergency Alert 1m ago
National Weather Service: A FLASH FLOOD WARNING is in effect for this area until 9:45 PM EDT. This is a dangerous and life-threatening situation. Do not attempt to travel unless you are fleeing an area subject to flooding or under an evacuation order.

Juniper Chen

nononononononononono
ooooo


it says to not go

the emergency alert said not to travel



Lucy Chen

It's very bad here



Water coming to garage

Monday/Tuesday

Assessment: garage flooded, need to remove soaked things

With parents working, 17 year old son steps in, decides to clear everything



- You never plan for crisis, but it forces action right away
- Changing status quo is traumatic, even if things were not perfect
- When the establishment or usual decision makers are absent, who steps in?

Tuesday/Wednesday:

Powerwash, start floor epoxy, sort garage contents



- **Crisis is a time to do a needs assessment**
- **Affected community has agency and can make a difference**
- **When the community is involved, they will not do it the same way as the establishment**
- **It may be messy, but they should be empowered**

Wednesday:

More rain, need to cover things on driveway, friends chip in

TM I can drop off two tarps

If you need any other fans or tarps we have one box fan and a few tarps Joe can drop off this afternoon!

GP We have pumps if you need them for standing water



- **Crisis is a time to ask for help and pull together allies**
- **Do not underestimate the power of personal connections**
- **People not directly affected by hepatitis are compelled by real life stories**

Thursday: Floor is done! Time to move things in



Garage had never been completely empty

- Disruption can be opportunity for a clean slate
- Can assess needs and redesign

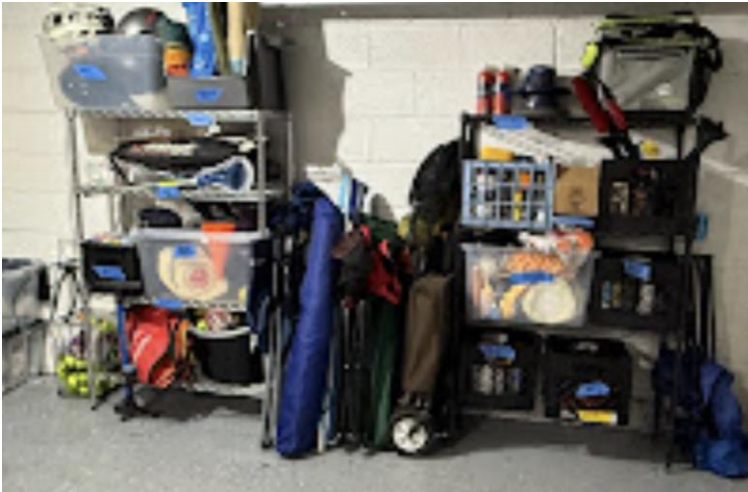


We used clear bins & baskets and labelled them (not done before, things got lost)

- Accessibility is key to engaging community
- Transparency combats misinformation & mistrust
- Use language that is meaningful with end users (will certainly be less boring)



Thursday: Reorganize the “new” garage



Because kids had sorted contents, they could help with reorganizing

- **Community should be part of the whole process- bringing in at the end is disorienting & not as impactful**
- **Make sure we are always educating: lay summaries, what this means for the community, etc**



We asked them to redesign so it made sense to them

- They put sports/outdoors equipment easy to access
- Removed the doors of a cabinet
 - Barrier from seeing contents
 - Repurposed for boots- previously hard to find
- **Ask affected community to design for their needs**
- **They will identify barriers & remove them!**

Friday: Wrapping up; made deadline to leave for vacation



- **5 days from crisis to completion**
 - Were it not for crisis & deadline, garage low priority (would have been put off)
 - **Disruption is not easy, but can be an opportunity**
 - **Chance for non-establishment to step in**



- **Kids excited about potential, dreaming up ideas**
 - Sons- workspace for building; Daughter- art/craft/cat space
 - **Establishment can't see what ppl with lived experience want**
 - **Let the affected community dream**



- **Kids now better invested; it is their space too**
 - **The affected community should not just be recipients, they should be co-owners**

Summary

- **Crises and deadlines mobilize energy & resources**
 - Viral hepatitis is an urgent crisis with an elimination deadline
 - It's time to use all our resources and networks
- **The affected community must be central to the response**
 - Community should be involved from the beginning
 - Community involvement can be messy, but leads to better results & increased access
- **As community members, let's recognize our own agency to make a difference & step up where we see gaps**
- **Working together during a crisis strengthens the relationships for the long run**



“The journey to ending the pandemic is not paved with policy papers, scientific publications and procurement plans

It’s carried on the backs of communities, and it needs to be led by communities.

Community action is what gives science its soul.”

-Rosemary Mburu, IAS 2025

