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# HEALTH & FAMILY

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ERIN HOOLEY/CHICAGO TRIBUNE

Sandra Abrevaya and Brian Wallach, shown in January 2020, created I AM ALS two years ago after Wallach was diagnosed with the disease at age 37.

BY ALISON BOWEN  
Chicago Tribune

When the COVID-19 pandemic hit, the entire world suddenly experienced living in fear that death could come for a friend or family member. The fear of death is what Brian Wallach and Sandra Abrevaya had already been living with.

The couple, former staffers for President Barack Obama and Kenilworth residents, started the nonprofit I AM ALS two years ago, after Wallach was diagnosed with the progressive nervous system disease at age 37. The terminal illness has no cure. Three years after a doctor expected he might be dead, Wallach has been able to watch his baby girls become toddlers.

For the first time last year, he said, he saw the world understand what it was like to live with fear. “This is the moment where we can seize the opportunity to educate people and help them understand,” he said.

The couple began the nonprofit after researching Brian’s diagnosis and realizing ALS is critically underfunded and under-researched, despite its brutal trajectory. With an average life expectancy of three to five years, many people don’t live long enough for drugs under development to benefit them. Wallach waited more than two years to receive access to one experimental drug.

I AM ALS focuses on harnessing the power of patients and their caregivers, who share experiences, raise awareness and advocate for a cure. Last year, they celebrated the second straight

## ALS cure needs greater urgency

COVID-19 vaccines show what’s possible. Kenilworth couple say it’s time to take that drive toward terminal illnesses.

year that the Department of Defense’s budget toward ALS research doubled, to \$40 million for 2021, and the National Institutes for Health promised to invest \$25 million over five years.

Through their volunteer network of patients and families, the group’s website now offers a dashboard to help people find clinical trials. Volunteers also created a rating system to assess whether clinical trial designs are patient-friendly and brought that data to drug companies to ask them to adapt their designs. I AM ALS also launched a patient navigation system.

COVID-19 made clear, Wallach and Abrevaya said, that when there is political will, there are ways to quickly inject funding toward a health challenge. Vaccines were created in a time frame that surprised experts; public health messaging became crucial to help people live safer lives.

Now, they said, it’s time to take that same urgency and funnel it toward diseases such as ALS that kill people quickly.

“Everything is on the line, and I hope people understand that now in a way that they might not have a year ago,” Abrevaya said.

In some ways, their nonprofit was prepared for this time. ALS patients’ lives become restricted and often are already mostly virtual. So followers and volunteers were ready to log on to computers and lobby policymakers. Legislation efforts include the ACT for ALS and the Promising Pathway Act that push for early access to drugs not yet approved by the Food and Drug Administration but that may help people with limited time to wait.

“We set the intention that we weren’t going to let this year slow us down, because ALS wasn’t going to slow down,” said Danielle Carnival, CEO of I AM ALS, about their goals for 2020.

Even before the pandemic, the family used caution around Wallach’s health. When COVID-19 hit, they doubled down. Like many people, their world became smaller; one challenge was the family and friend support they

typically lean on was no longer available. But there were some bright spots. Friends gathered in the couple’s yard to surprise them with caroling over the holidays and hung presents from the trees. Neighbors set up trick or treating for the girls where Wallach could go with his scooter before anyone else was out.

Wallach is quick to compliment Abrevaya’s ingenuity in helping their toddlers “enjoy life and experience some normalcy in the midst of the insanity,” noting the inflatable pool he found in their backyard with multiple inflatable things in all shades of pink for the girls.

Despite Wallach’s upbeat Twitter account showing everything from Peloton bike rides to a boat nap with their oldest daughter, the year hasn’t been easy.

In the past year, Wallach’s voice has become weaker, and he has chosen to use a wheelchair. The family requested it, he noted, after multiple falls. His Twitter feed, which recounts his efforts and adventures, showed him racing

his daughters, a newfound ability to keep up with them, if on wheels.

“For someone who is nearly four years into this thing, I feel lucky, one, to be here and, two, to be able to do everything that I’m doing,” he said.

Abrevaya jokes that Wallach’s demeanor is such that he is always ready to interject, “The good news is ...”

As someone used to sprinting through airports, he said, the change to a wheelchair and voice weakening was an adjustment.

He added, “On the flip side” — his wife interrupted, smiling, “The good news is ...” — that mentally he feels sharper than ever and confident this work is valuable. “It makes life incredible,” Wallach said.

Next up, they plan to hold President Joe Biden accountable for his recent vow to put \$50 billion toward diseases including ALS and to set up a separate agency seeking cures.

Last year, government showed how to carve a path for lifesaving research and treatments, Carnival said. “We knew we could do this, but now we have an example of how to do this for other diseases.”

And COVID-19 has helped pave a way for tackling tough topics such as disease and death.

“It sort of gives space to have these candid conversations,” Wallach said. “Hope is the embrace of the unknown, and acting, even though you don’t know who your actions will benefit, or when they will come to fruition. I think 2020 was a year that tested hope.”

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## Tart shows off scariest of fruits

BY BEN MIMS  
Los Angeles Times

Every winter, I anticipate buying nothing but citrus. Walking the farmers market aisles, I get too excited by the sight of it to resist grabbing as much as I can carry before my tote bag’s straps start bruising my shoulders.

The citrus that calls to me most is Buddha’s hand citron, that tentacled yellow hand from the black lagoon that you may have seen at some stands and gawked at in horror.

I laugh from the looks I get as I walk up and ask for a half-dozen

while everyone around me, buying normal oranges and mandarins, grimaces in queasy confusion.

Buddha’s hand — a variety of “open-hand” citron in which the “fingers” of the fruit splay outward rather than inward — is an anomaly in the citrus world because it’s all pith covered in zest; there’s no pulp. The zest is heavily fragrant and sharp but softer than lemon. Further differentiating, its pith is barely bitter at all, so you can eat it raw.

In years past, I’ve always cut it into chunks and used it to make marmalade with less sugar than is

needed for orange peels. But this year, as a redirect from the endless cakes and cookies I made during the holiday season, I’m making a tart with it. And when thinking about the bitter-less qualities of its pith, my mind goes straight to Shaker lemon pie.

Traditionally, Shaker lemon pie is made with whole slices of lemon, rind and all, surrounded by custard and baked in a simple pastry crust. The lemon slices are macerated in sugar overnight to soften their texture and their bite.

With my version, though, I can

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