PATER Volume 3 ISSUE 3



SPECIAL POINTS OF INTEREST:

Hear about being a long distance caregiver, gives you a fresh perspective on life, health and the benefits of technology

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From Chief Executive to Chief Caregiver

This Is Personal.

By Cathleen McBurney

When Martin Pellinat discusses his parents, you can't help but notice the pride and awe in his voice. Not only does he love them, but he respects them.

That same pride and respect carries over into what VisionTree is doing to change the patient / caregiver landscape for the better.

I had the pleasure of sitting down with Martin (who happens also to be my team mate) to discuss how caring for his parents have helped him understand how to better serve both patients and their caregivers. And he has a lot to say.

Tell me a what led to your role of caregiver...

My parents are my heroes. They are both German immigrants who escaped the east, as the Berlin Wall was being built and came to America for a better life. My father, now 95, and mother, now 89, have been blessed to live long and active lives and for the last 30 years as retirees in their community in Alabama.

Recent colorectal and heart health issues led to a wise move to assisted living. In doing so, as an only child, the coordination of care at a distance in California, led to being an involved, family caregiver for both parents.

What do you think is the most difficult part of being a caregiver?

There are key terms that embody being a caregiver - care coordination, patient navigator and patient advocate. As a committed and primary caregiver you take on each of these roles, which include management of health data / records, appointment, care team and insurance contact management and getting second opinions, if needed, for the best treatment pathways possible.

What would make your caregiver role easier and more effective?

There are many great communities and tools that have been formed and are available for caregivers to help patients such as: patientslikeme, foundations, clinicaltrials.gov and others.

Finding and joining patientcentered communities to access resources, clinical trials and share personal experiences to assist with treatment option decision making and home health care is always beneficial and a key goal.

Tell me how your role as a caregiver led to the creation of One For The Cure?

One for the Cure (O4TC - https://oneforthecure.org)

For my parents and our family, we believe that listening to our care teams, seeking advanced treatments with the best quality of life results, along with strength and perseverance, gives us a path forward, and it most certainly has resulted in a long life for my parents and we believe many more years to come. By having a mobile, cloud-based portable health record with communication and data sharing tools, provides a secure means of organizing key information and a voice for the patient at every step of their treatment pathway and survivorship journey.



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What gives you HOPE on your journey as a caregiver?

"Being able to see them enjoy each day, happy and healthy, and make sure we are prepared to stay on top of things to keep making a difference in the world"



One For The Cure...Coordinating Care For Families

Can you expand on some of the features One For The Cure offers to patients and their families?

The One For the Cure app and portal, provides us with several key benefits including:

- Access to your own HIPAAcompliant Portable Health Record
- Patients or caregivers can manage files, contacts and calendar for appointments
- Find and match with clinical trials using: www.clinical trials.gov
- Utilizing the Optimal Care (VTOC) platform in use and supported with 2M+ patient worldwide
- Join the TREE of HOPE patient community

Can anyone sign up for a One For The Cure account?

Yes! Anyone can sign up for a free One For The Cure Account. It's a great opportunity to gather all your important medical records into one space. In my case, the Contact section has been very helpful for organizing all the different doctors and care team members. I have all the information at my fingertips, which makes it much easier to book appointments for them.

The calendar section is extremely helpful as well. I can put all of my parents appointments on this one calendar. When you have two people seeing multiple doctors, you need an easy way to coordinate. This account has done that for us.

My parents really liked joining the Voice For Hope community. For them, being able to share a small part of their story with others was meaningful and empowering, and they feel their voice is being heard.

HOPE is the same in any language



Did You Know...21st Century Cures Act

The 21st Century Cures Act, which goes into effect in 2020, expands how patients access their own personal medical records. Patient Data Access provisions in the law promote expanded health data interoperability between providers, payers and state health information exchanges. Those same entities will also be required to more seamlessly exchange patient data with each other.

One For The Cure is giving patients a singular personal health record that they can populate and then share with others. Once 21st Century Cures Act goes into effect, patients will be able to transfer their PHI from many portals into one. One For The Cure.



"My parents are my heroes. They are both immigrants and came to America for a better life."

Contributing Editor: Cathleen McBumey

