PicnicHealth

Get Organized and Get Ahead with PNH in the New Year

To learn more visit: picnichealth.link/newyearpnh

Agenda

- Overview of PicnicHealth and our PNH research
- Tips and tricks for getting organized this year with Erin Fortin and Brandi Lewis
- Q&A

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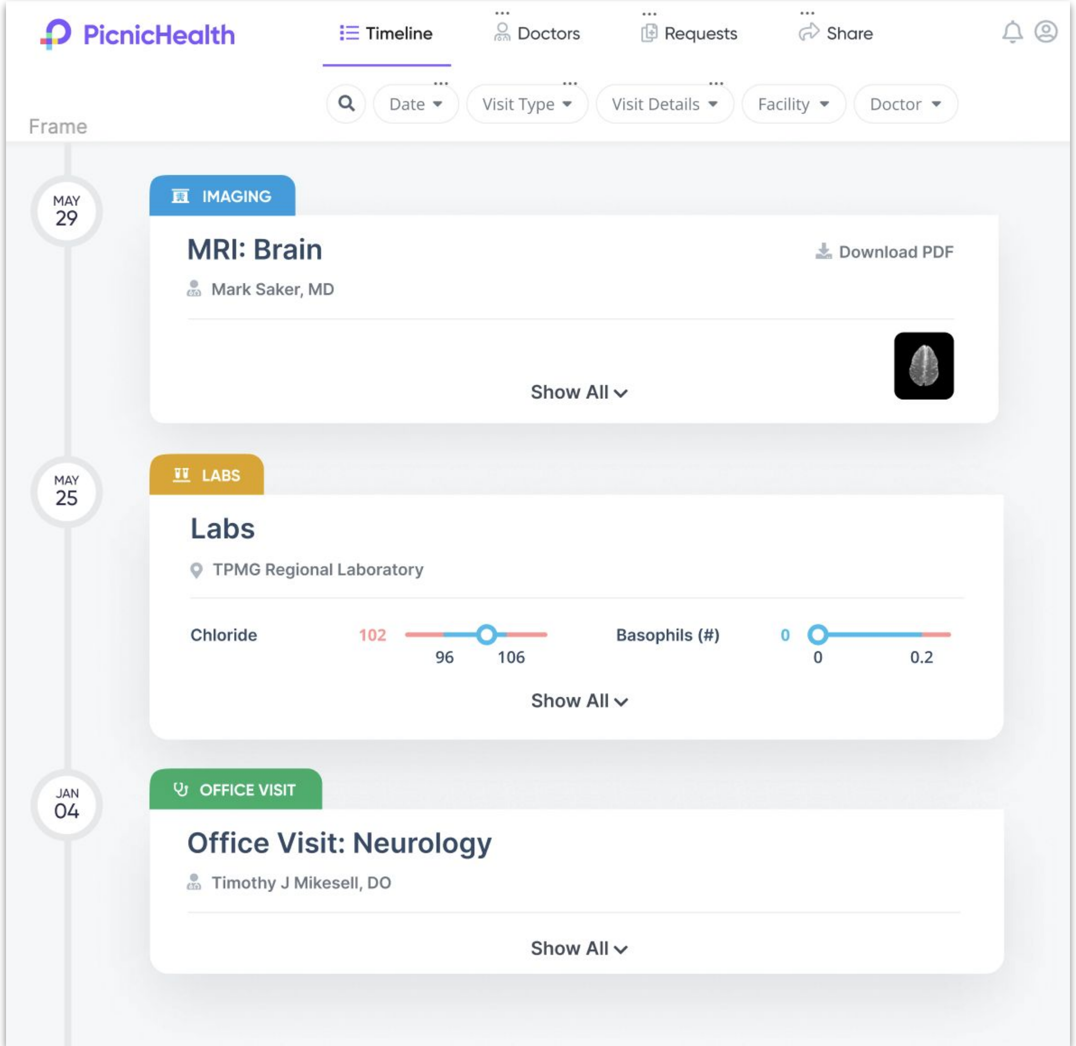
PicnicHealth

Overview of PicnicHealth

A tool to help you access and share your medical records securely



MAY 29
IMAGING
MRI: Brain
Download PDF
Mark Saker, MD
Show All

MAY 25
LABS
Labs
TPMG Regional Laboratory

Chloride	102	96	106	Basophils (#)	0	0	0.2

Show All

JAN 04
OFFICE VISIT
Office Visit: Neurology
Timothy J Mikesell, DO
Show All

With PicnicHealth’s Timeline you can:

- Access all your medical records **in one place** without logging into multiple portals
- **Easily search** by date, visit type or doctor
- Track your lab values over time **regardless of where you get care**
- **Securely share records** with family and doctors to keep them in the loop
- Download **original source documents**

Medical records are important to real-world data research in PNH

Real-world data (RWD) is data that relates to a person's health status, which can include doctor's and ER visits. It can come from a number of sources, including your electronic health records (EHRs).

Why does this matter for PNH?

- Help doctors better understand total burden of disease, including fatigue
- Find treatments that better manage PNH symptoms and are easier to take
- Help us better understand the trajectory and complications of PNH

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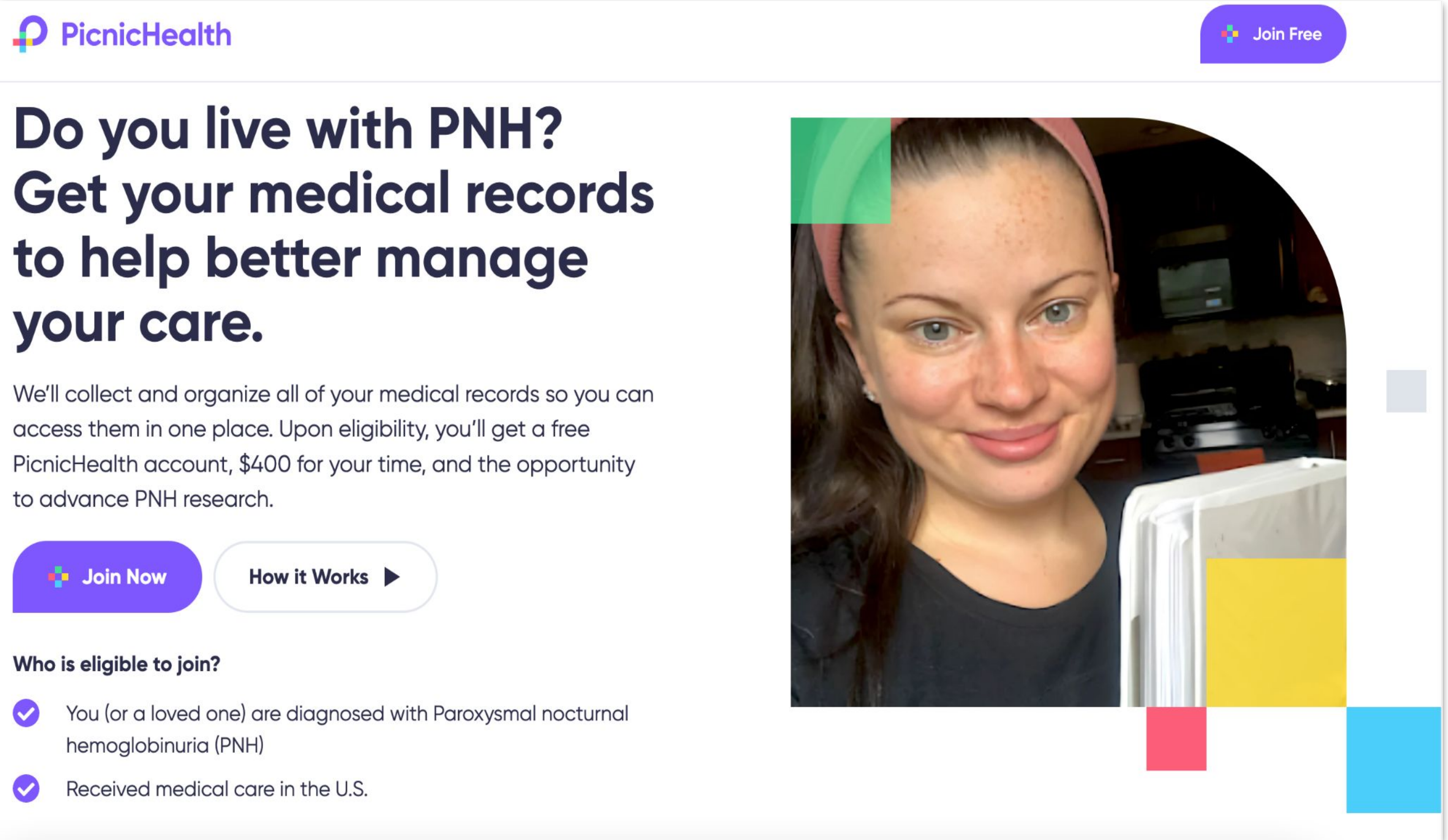
Our real-world data research program in PNH

Sign up from the comfort of your home in **10 minutes or less.**

With low barriers to participation, **our research includes people whose stories have never been told** in traditional trials.

When you join, you get:

- Free access to the Timeline
- $400 for contributing to research
- The opportunity to participate in real world data research for PNH



Do you live with PNH? Get your medical records to help better manage your care.

We'll collect and organize all of your medical records so you can access them in one place. Upon eligibility, you'll get a free PicnicHealth account, $400 for your time, and the opportunity to advance PNH research.

Who is eligible to join?

✓ You (or a loved one) are diagnosed with Paroxysmal nocturnal hemoglobinuria (PNH)

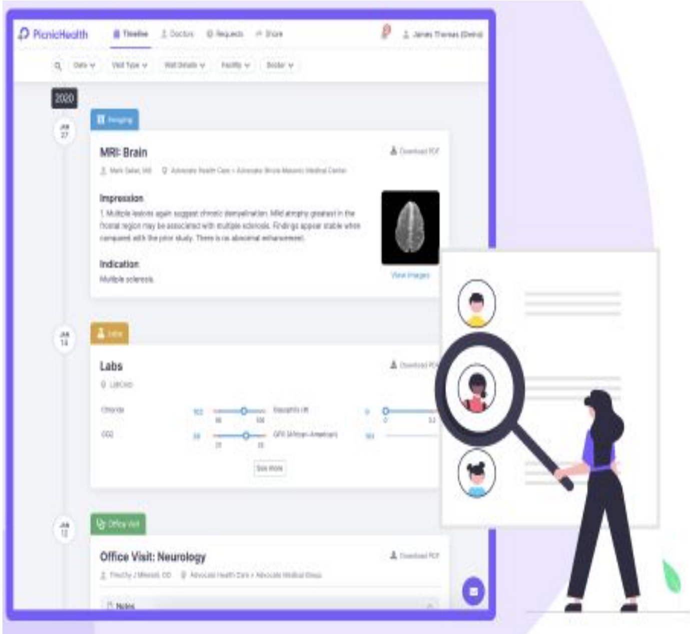
✓ Received medical care in the U.S.

Learn more and sign up:
picnichealth.link/newyearpnh

Your participation has a powerful impact in real-world data research

PicnicHealth Solution

Every person living with PNH has a story and PicnicHealth captures those stories via medical records to advance research.



- PicnicHealth is recruiting ~**100 patients** with a confirmed PNH diagnosis within the next few months
- After sign-up, you will also be asked to complete **optional paid surveys** to help researchers learn more on **the real day-to-day impact of living with PNH**
- Through de-identified medical records **REAL people and REAL stories** are used to help researchers

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Our research principles

THESE ARE PROMISES WE MAKE TO THE COMMUNITIES WE WORK WITH:

Protect rights and privacy.

We use the same, or better, privacy and security practices than your doctor’s office.

De-identify data.

Before researchers receive any data, we remove any and all personally identifiable information.

Representative data.

Commitment to collecting diverse and representative datasets through community partnerships.

Informed consent.

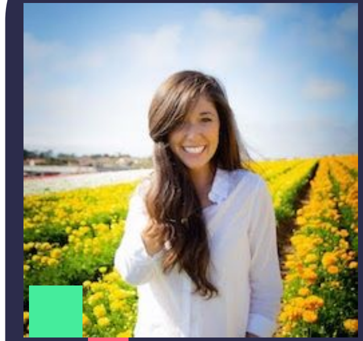
Participants must proactively opt in through informed consent.

Withdraw at any time.

If participants would rather not participate in research anymore, we fully respect their decision.

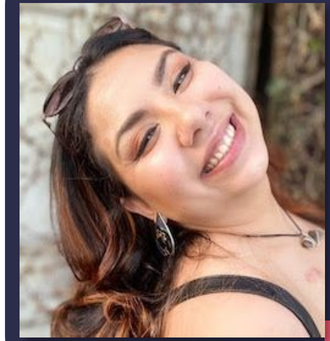
To learn more visit: picnichealth.link/newyearpnh

Real people, real stories



"Being diagnosed with a rare illness was overwhelming in many ways and managing medical records from multiple physicians was like a full-time job. **With PicnicHealth's Timeline, I was able to eliminate the tedious work and stress of managing my records allowing me to focus on my care and living**! PicnicHealth makes it possible for patients like you and I to have a voice in the medical research community."

Chelsea | PicnicHealth Research Participant



"PicnicHealth has positively impacted my health care journey by **helping me compile my records to better advocate for my health.** They also helped me to participate in research in the hopes that this information helps scientists and physicians identify patterns in symptoms and treatments to better the lives of patients."

Elisa | PicnicHealth Research Participant

Thank you for joining us!
Any questions?

Interested in signing up?

picnichealth.link/newyearpnh

More questions?

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