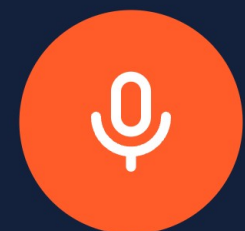


Recover Lost Evidence

Voice notes capture what families notice between surveys

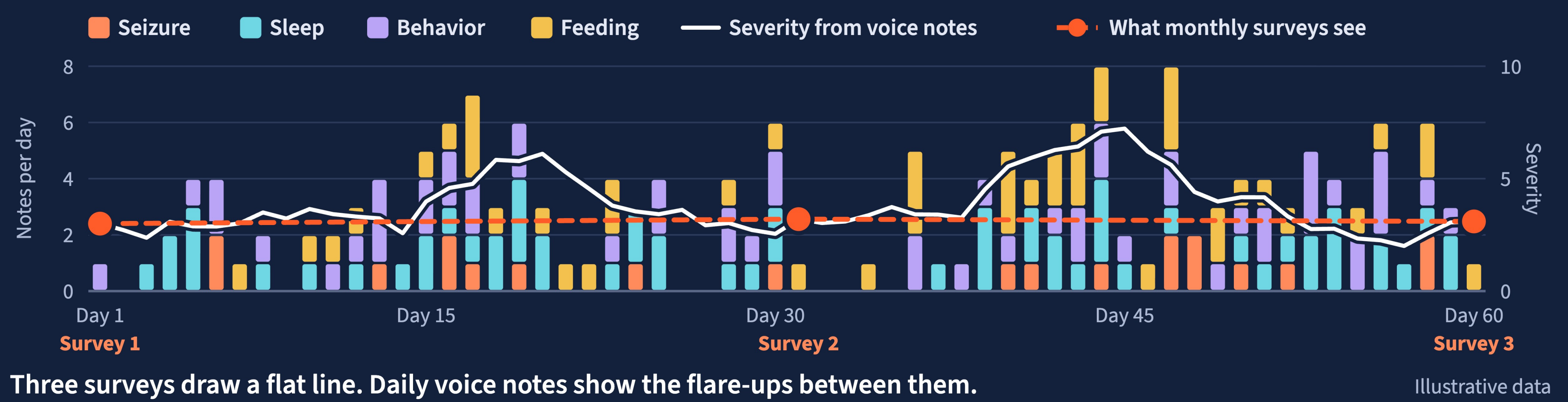
Principal Investigators: Sarah Poliquin, PhD · Melissa Thelen · Ashlee Manjón-Stierstorfer
NR2F1 Foundation · Forma Health



WHAT IS LOST EVIDENCE?

Everything a patient or caregiver **notifies** but doesn't record, write down, or remember.

A survey captures one moment. A short voice note keeps the detail from the days between.



1 Case study: NR2F1 Natural History Study

Families of people with BBSOAS use voice notes to record what they notice, every day

BACKGROUND

The NR2F1 Foundation aims to fast-track treatments for Bosch-Boonstra-Schaaf Optic Atrophy Syndrome (BBSOAS), a neurodevelopmental disorder caused by variants in the NR2F1 gene.

Its natural history study maps BBSOAS symptoms over time to help select clinical trial endpoints, and builds an accessible database for researchers.

ONE VOICE NOTE, MANY DATA POINTS (illustrative example)

WHAT THE PARENT SAYS

"Maya followed the light from the window with her eyes today, first time! She only napped 40 minutes and had a big meltdown before dinner. She coughed twice drinking water."



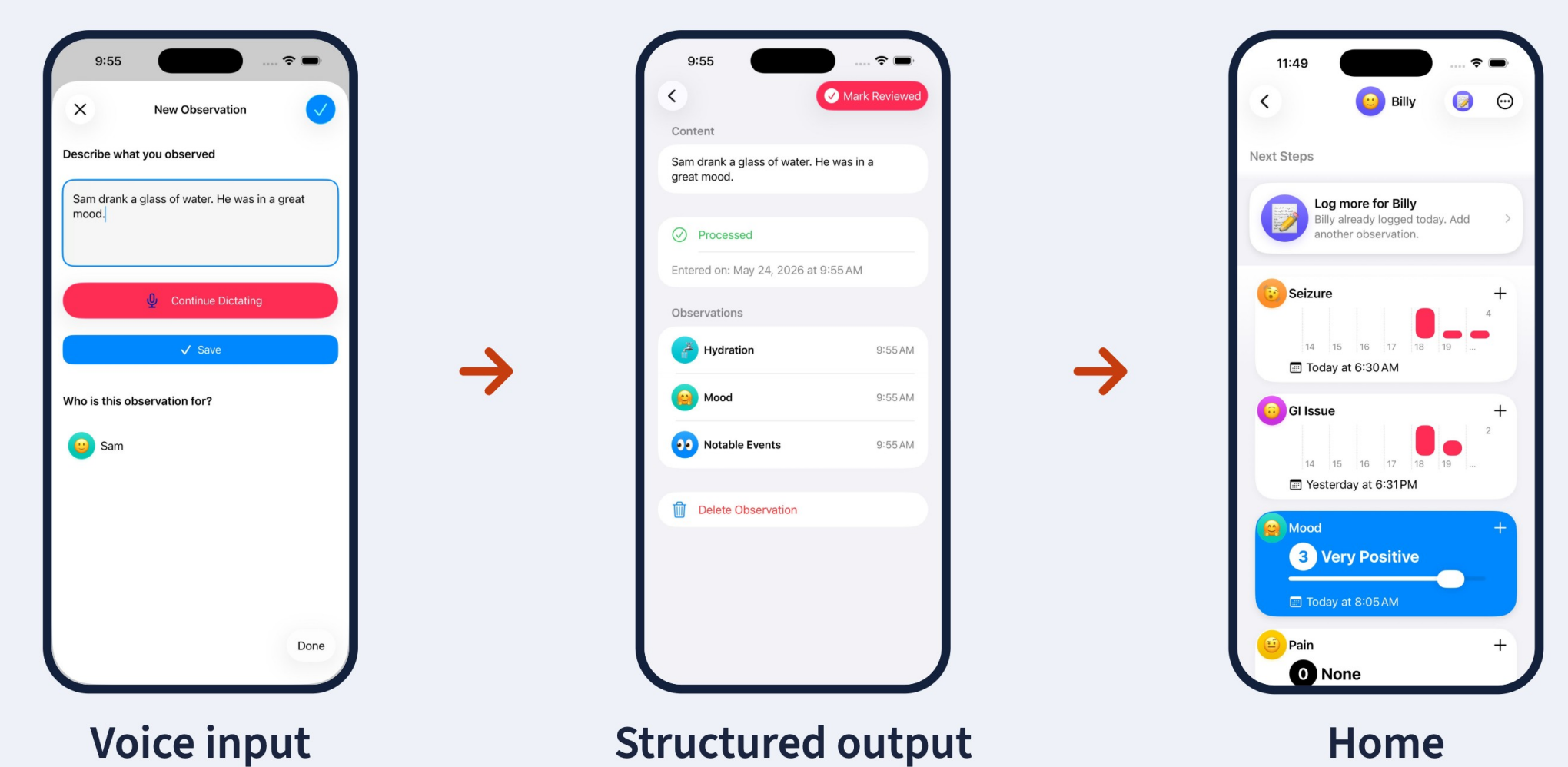
WHAT THE STUDY RECEIVES

Vision · New skill Visual tracking	Sleep · Nap 40 min
Aberrant Behavior · Meltdown Before dinner	GI & Feeding · Coughing on liquids 2 times
Time (automatic) 5:40 PM today	Reported by Parent

HOW THE LOG APP IS USED

- ✓ Symptom tracking at home by voice, text, or quick taps
- ✓ AI codes each voice note to the BBSOAS disease concept model
- ✓ Each entry is time-stamped and tied to the participant's study record

THE LOG APP



2 Everything between the surveys

Each note maps to a topic and tag in the BBSOAS disease concept model coding tree

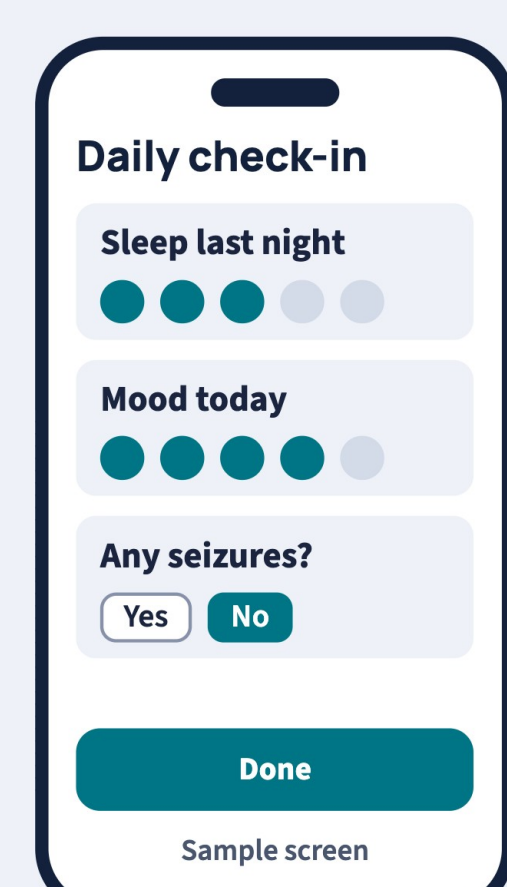
BBSOAS disease concept model 15 topics · 690 tags

Seizure 98 tags	Aberrant Behavior 79 tags	Sleep 13 tags	GI & Feeding 33 tags	Daily Living Skills 27 tags
Medication 104 tags	Communication 45 tags	Health & Life Events 69 tags	Vision 41 tags	Social & Play 36 tags
Side Effects 28 tags	Motor Skills & Tone 49 tags	Therapy Sessions 25 tags	Cognition 26 tags	Global Impression Scale 17 tags

3 Built for observational studies

Voice notes sit alongside the measures a natural history study needs

10-SECOND DAILY SURVEYS



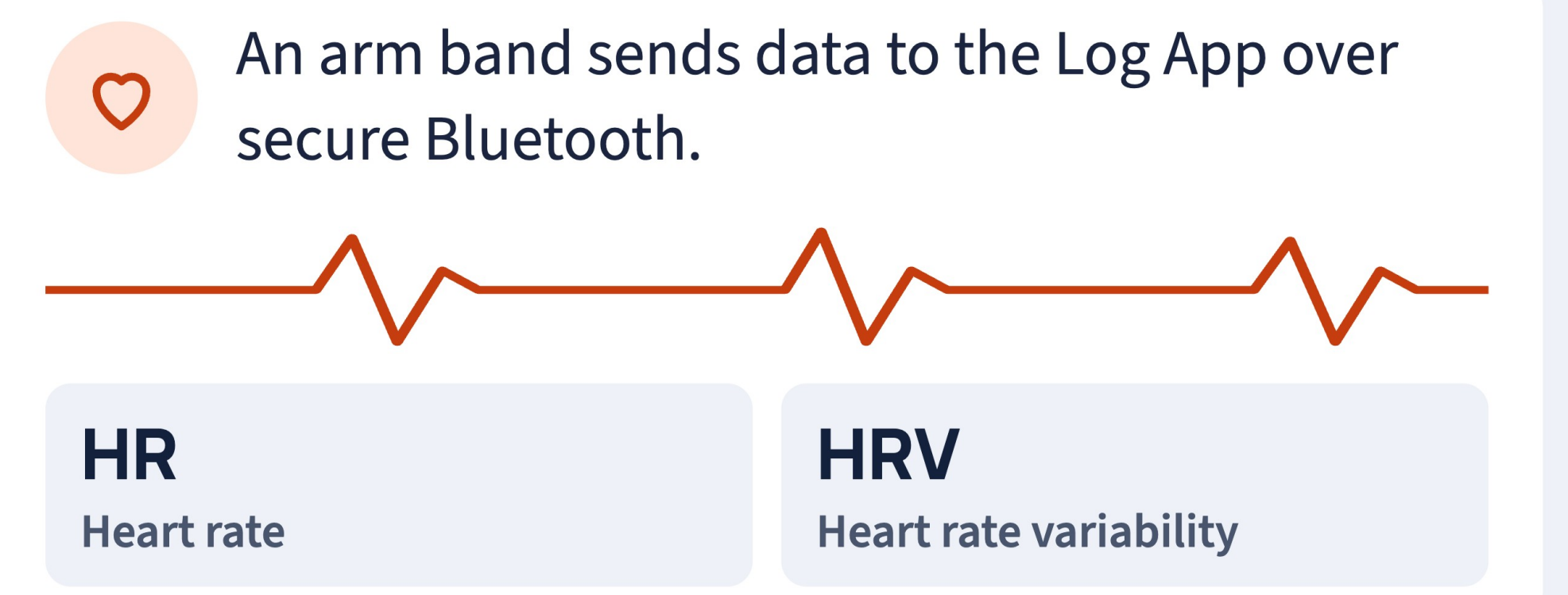
< 10 s

Simple questions, once a day, that take less than 10 seconds to answer.

VALIDATED NEUROLOGICAL INSTRUMENTS

Trail Making Test	Processing speed, set-shifting
Verbal Paired Associates	Associative memory
Digit Span	Working memory
Simple Reaction Time	Response speed
Choice Reaction Time	Decision speed

HEART RATE SENSOR



WHAT MATTERS TO THE COMMUNITY

Invite other caregivers	Daily notifications	English, French, Spanish
Charts	Customized inputs	Quick-access widgets

ONE PARTICIPANT, LINKED RECORDS



Share this poster

See how to recover lost evidence in your study

formahealth.io/poster/combinedbrain2026

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GET THE LOG APP

