
20TH
Site Solutions Summit™
ANNIVERSARY

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Site Solutions Summit™

Redefining Familial ALS
THE PATIENT VOICE

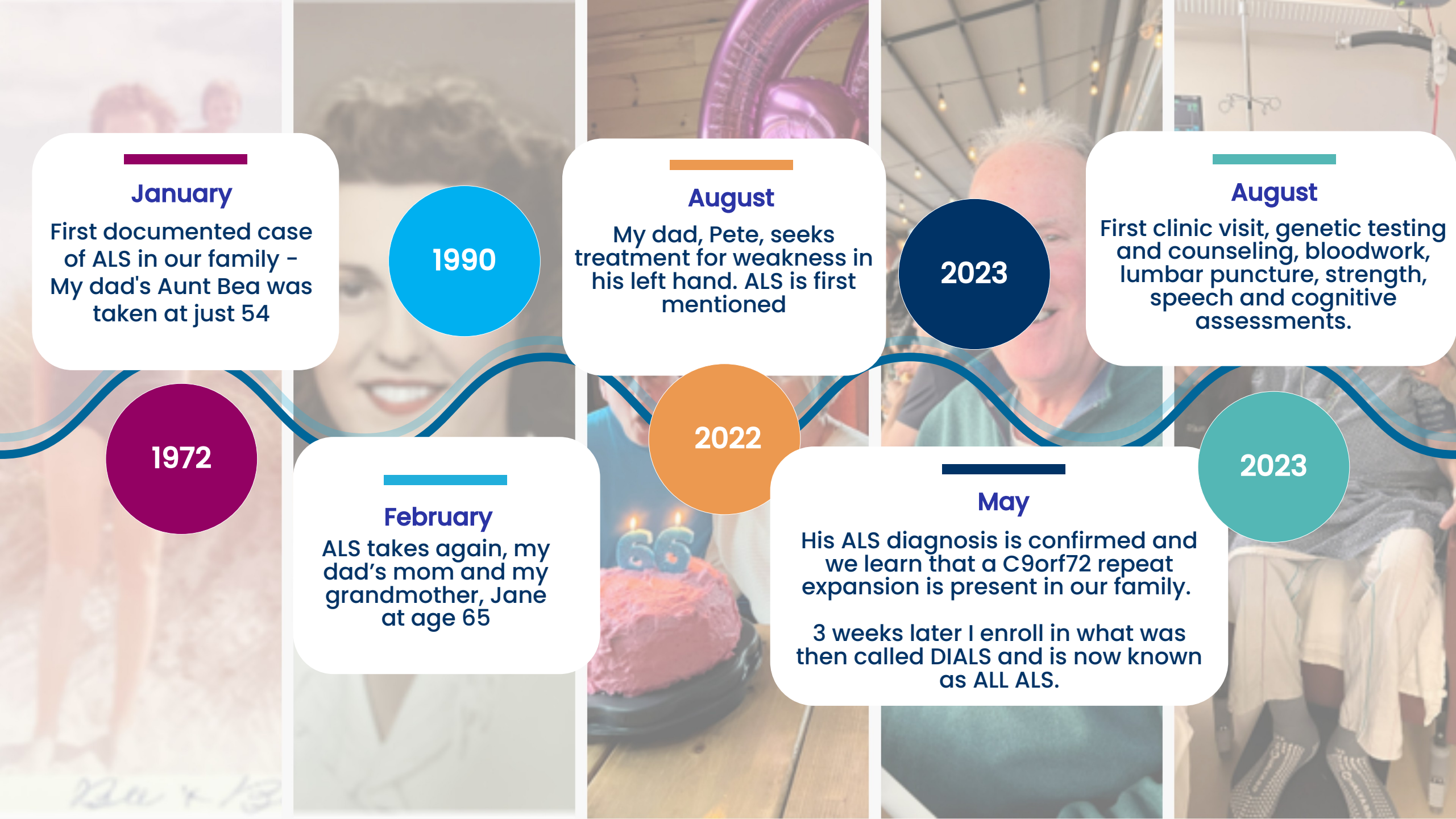
October 17, 2026

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SCRS
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January

First documented case of ALS in our family - My dad's Aunt Bea was taken at just 54

1972

1990

February

ALS takes again, my dad's mom and my grandmother, Jane at age 65

August

My dad, Pete, seeks treatment for weakness in his left hand. ALS is first mentioned

2022

May

His ALS diagnosis is confirmed and we learn that a C9orf72 repeat expansion is present in our family.

3 weeks later I enroll in what was then called DIALS and is now known as ALL ALS.

2023

August

First clinic visit, genetic testing and counseling, bloodwork, lumbar puncture, strength, speech and cognitive assessments.

2023



October 17, 4PM

My disclosure visit, I learn that I test positive for the pathogenic repeat expansion in C9orf72

2023

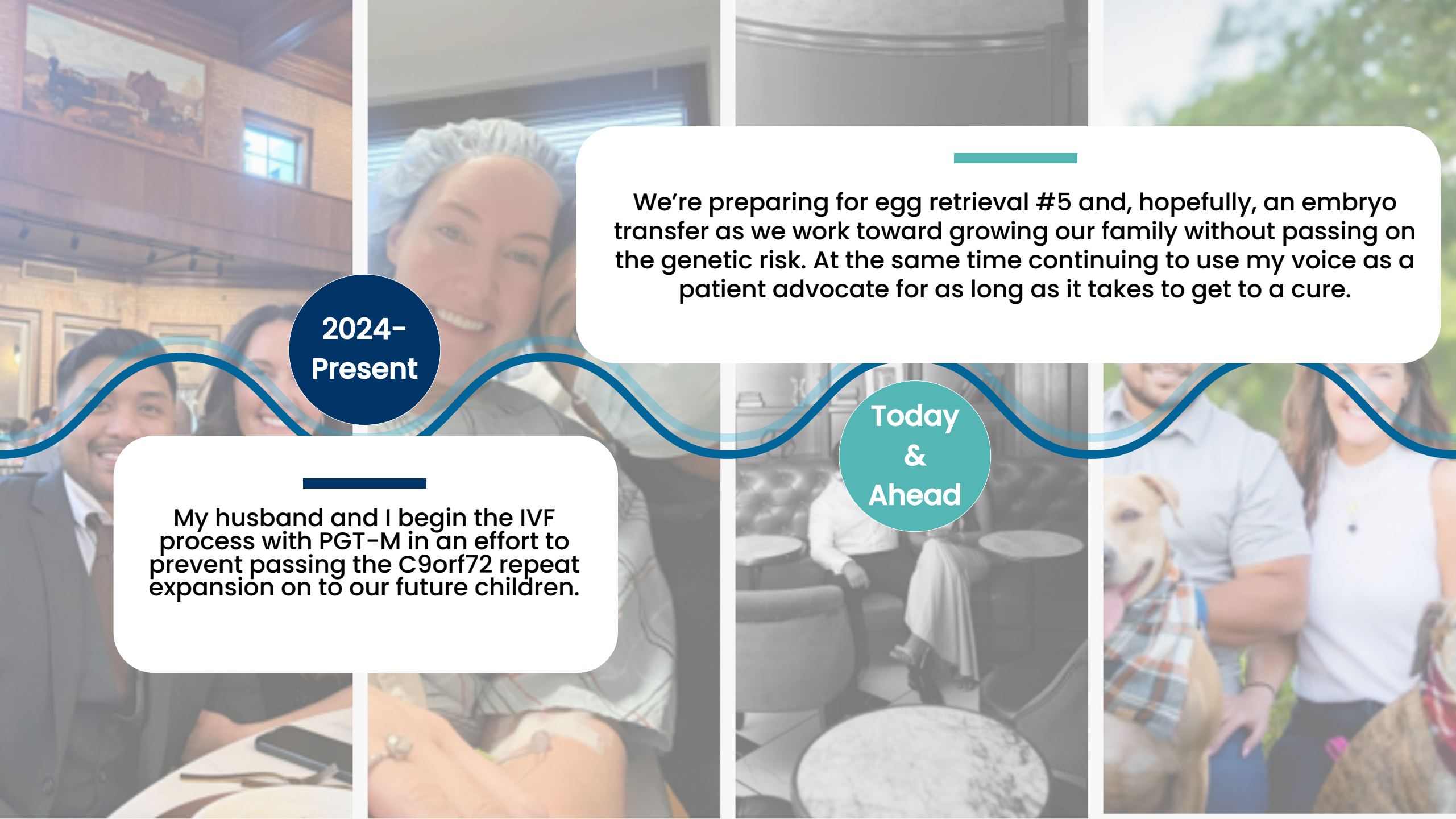
2024

June 26

My dad passes away from ALS, 11 days after his 67th birthday.

I continue participating in natural history research through ALL ALS PREVENT and ALS TDI's ARC Study, while becoming increasingly involved in ALS advocacy. Sitting on patient advisory committies at Target ALS and Massachusetts General Hospital/Healey MyMatch

2024-2026

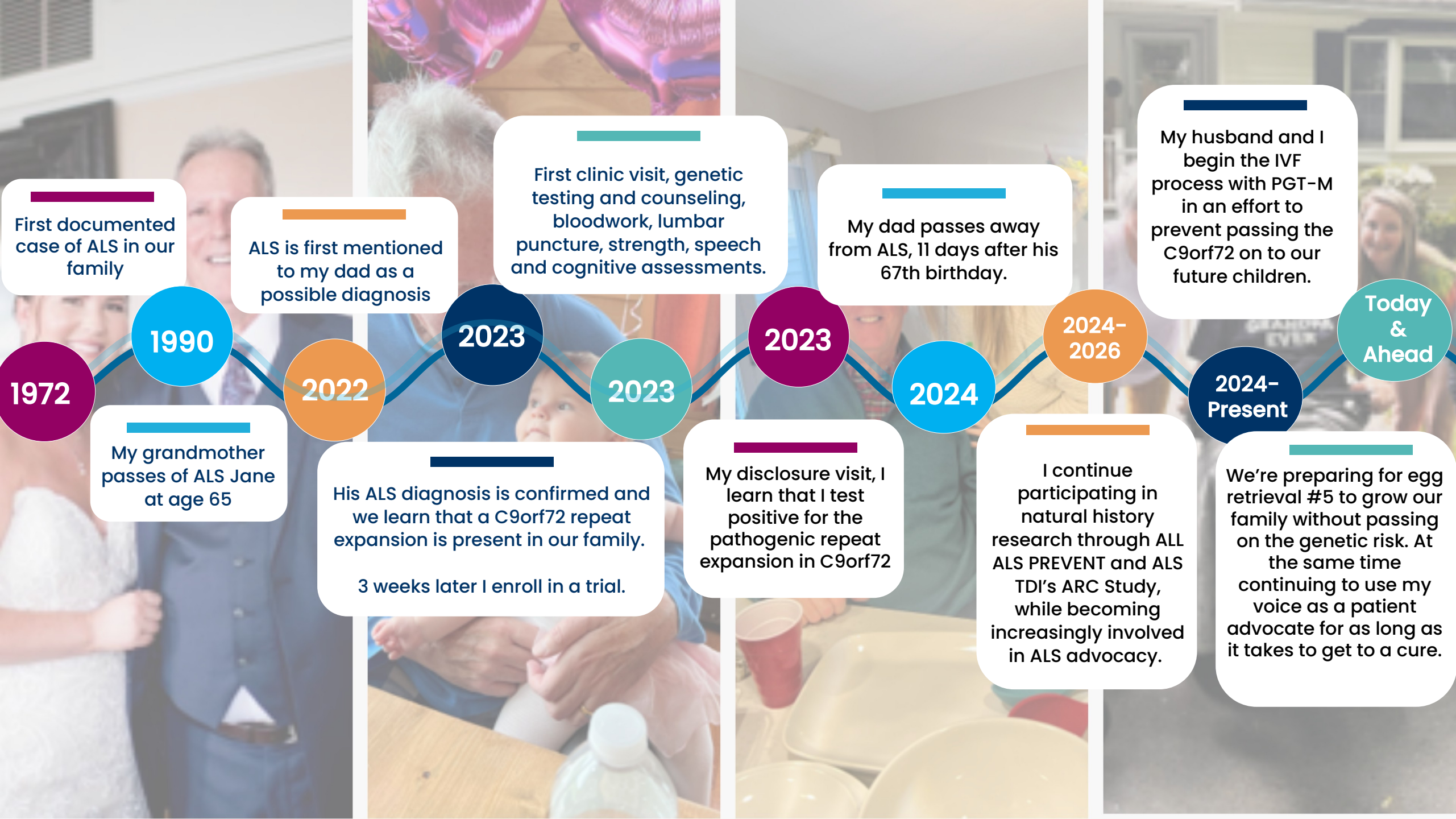


2024-Present

My husband and I begin the IVF process with PGT-M in an effort to prevent passing the C9orf72 repeat expansion on to our future children.

Today & Ahead

We're preparing for egg retrieval #5 and, hopefully, an embryo transfer as we work toward growing our family without passing on the genetic risk. At the same time continuing to use my voice as a patient advocate for as long as it takes to get to a cure.



1972

1990

First documented case of ALS in our family

2022

ALS is first mentioned to my dad as a possible diagnosis

My grandmother passes of ALS Jane at age 65

2023

First clinic visit, genetic testing and counseling, bloodwork, lumbar puncture, strength, speech and cognitive assessments.

2023

His ALS diagnosis is confirmed and we learn that a C9orf72 repeat expansion is present in our family.

3 weeks later I enroll in a trial.

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WELCOME TO OUR SCRS MEMBERS AT GLOBAL!



- Accelerated Clinical Trials
- Access Community Clinical Trials
- Accurate Clinical Research
- Acevedo Clinical Research Associates
- Activian Clinical Research
- Adams Clinical
- Advanced Clinical Research
- Advanced Medical Research Group
- Advanced Research Institute
- AdventHealth
- Advocate Health National Center for Clinical Trials
- Agile Clinical Research Trials
- AIM Trials
- Albuquerque Clinical Trials
- Alcanza Clinical Research
- Alfa Medical Research
- Allergy, Asthma & Sinus Center
- Alliance Clinical Network
- Allied Research Society Colombia
- ALSA Research
- Altruistic Clinical Research
- Altus Clinical Research
- Ambassador Clinical Research
- AME Clinical Research
- American Clinical Trials
- AMR Clinical
- Aotearoa Clinical Trials
- APD Clinical Research
- Apex Clinical Studies
- Apex Trials
- ARENSIA Exploratory Medicine GmbH
- Arizona Clinical Trials
- Arizona Research Center
- Ascend Clinical Research
- Assured Clinical Research
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- Avacare
- Avanza Medical Research Center
- Avera Research Institute
- Avicenna Clinical Research
- Avita Clinical Research
- AXCES Research Group
- Bay Pines Foundation
- Be Well Clinical Studies
- Berkson Medical
- Biopharma Informatic
- BioPharma Select
- Birmingham Clinical Research Institute
- Biscayne Clinical Research
- Bodyline Medical Clinic
- Boeson Research
- Bold City Clinical Research
- Bond Health
- Boots UK
- BOSQUE CLINICAL RESEARCH
- Bradenton Research Center
- Bright Future Research
- Brooklyn Clinical Research
- Cardiovascular Institute of Northwest Florida
- Care Access
- CaRe Clinic
- Cedar Crosse Research Center
- Cedar Health Research
- CenExel
- Central city clinical hospital of Ivano-Frankivsk city council
- Central States Research
- Centricity Research
- Centro de Estudios Clinicos SAGA
- Centro Oncologico Personalizado, COPE
- Charter Research
- Chase Medical Research
- Chicago Clinical Research Institute
- Chicago Medical Research
- CIPREC
- Circle Clinical Research
- Civia Health
- Clearwater Cardiovascular Consultants
- Clever Medical Research
- Clinical Research Institute
- Clinical Research of Central Florida
- Clinical Research Partners
- Clinical Research Philadelphia
- Clinical Trials of Texas - A Flourish Research Site
- Clinitiative Health Research
- ClinSurge Research
- ClinTrial Research
- ClinTrial Research Network
- CN Clinical Research
- CNS Healthcare
- Coastal Medical Research
- Collaborative Clinical Research, Virginia iSpine Physicians
- Colorado ENT & Allergy
- Conquest Research
- Core Clinical Trials
- CRISMO
- Cross Creek Medical Clinic
- CTI Clinical Research Center
- Cullman Clinical Trials
- Deaconess Research Institute
- Del Sol Research Management
- Diamond Research Center
- Diverse Clinical Research
- DM Clinical Research
- Dolphin Medical Research
- DPMG Clinical Research
- Dr Deshinee Moodley
- Duke University
- Duke University School of Medicine
- Durham Research Collaborative
- Eagle Clinical Research
- East Valley Diabetes & Endocrinology/Clinical Research
- Elevate Clinical Research
- Elite Clinical Research
- Elite Research Network
- Elligo Health Research
- EmCrown Clinical Research
- Emerge Research Institute
- Emeritus Research
- Emerson Clinical Research Institute
- Eminat
- Empathx Catalina Research Institute
- Empathx Clinical Research
- EMS Healthcare
- EmVenio
- Endpoints
- Enroll
- Entrust Clinical Research
- Envoy Clinical Research
- Epic Medical Research
- Era Health Research
- Essential Medical Research
- Eunix Clinical Research
- Evolution Research Group
- Exalt Clinical Research
- Eximia Research
- Florida Clinical Trials Group
- Flourish Research
- Flourish-ENCORE Research
- FOMAT Medical Research
- Frontier Clinical Research
- Fundacion Estudios Clinicos
- Fundación PITA
- Future Life Clinical Trials
- Future Medical Research
- FutureMeds
- Gabrail Cancer and Research Center
- Gateway Clinical Trials
- Genesis Orthopedics & Sports Medicine
- Global Clinical Trials
- Global Medical Institutes
- Grupo Sur Investigación Clínica
- Guardian Research Organization
- Halo Clinical Research
- Hanson Clinical Research Center
- Headlands Research
- Homestead Associates in Research
- Hometown Urgent Care and Research
- Horizon Clinical Research
- Houston Methodist
- hyperCORE International
- I Fit Out
- Icahn School of Medicine at Mount Sinai

WELCOME TO OUR SCRS MEMBERS AT GLOBAL!



Ideal Clinical Research
Illinois Bone & Joint Institute
IMA Clinical Research
Imax Clinical Trials
Infigo Clinical Research
Infinite Research Group
InSight Health Clinical
Insight Health Systems Clinical Research
Inspira Health
Instituto de Investigaciones Clínicas Córdoba
Integrity Clinical Network
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Irvine Clinical Research
iTrials
IVX Health
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James Clinical Research
Japan Association of SMO
Javara
Jedidiah Clinical Research
K2 Medical Research
Kalo Clinical Research
Kelsey Research Foundation
khann
Kinetic Clinical Research
Lacy & Barrett
Lakeview Institute of Clinical Research
Latin Clinical Trial Center/ PhaseWell Research
Legacy Clinical Trials
Legacy Research Center
Lightship
Lumen Clinical
Lumi Research
Lynd Clinical
Lynn Health Science Institute
Magnolia Clinical Research
Mankato Clinic - Javara Research
Mazzoni Center
Mediclaris Clinical Research
Meditrial
Medovation Clinical Research
MedX Clinical Research
Meera Clinical Research Institute
Memorial Sloan Kettering
MemorialCare
Momentum Clinical Research
Monroe Biomedical Research
Montana State University
MRx Sites
National Eagle Research
National Institute of Clinical Research
Neighborhood Healthcare
Neuropsychiatric Research Center of Southwest Florida | An ERG Portfolio Company
Neutra Life Sciences
New Generation of Medical Research
NewGen Health Group
Nexara Institute
NexGen Clinical Research
NextPhase Research Florida
Nezar Clinical
NICR
NMC Research
Northshore Research Associates
Northwell Health
Notist
Nova Fortis Clinical Research
NoviTrial
NW FL Clinical Research Group
ObjectiveHealth
Omnicure Clinical Research
One of a Kind Clinical Research Center
Ophir Clinical Research
Optimal Research Sites
Oscar Clinical Trials
Panthera Biopartners
Pediatric Research of Charlottesville
PGA Medical Research
PharmaDev Clinical Research Institute
PhaseWell Research
Pinnacle Research Group
Pioneer Research Group
Pollak Clinical Research Consulting
Populace Health
Pratia
Preferred Primary Care Physicians
Prestige Clinical Research Network
Prime Medical Research
Prime Site Research Solutions
Primeway Clinical Research Group
Profound Research
PT&R
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Quality Medical Research
Randomize Now Research Centers
Rare Disease Research
RAYUS Radiology
Remington Davis
Reno Clinical Trials
Renstar Medical Research
Research Works
Revival Research Institute
Riveldi and Associates
Rocky Mountain Clinical Research
Rovia Clinical Research
RX Trials
S4 Research
Sagebrook Behavioral Health
Sanatorio 9 de Julio - C.I.C.E. 9 de Julio
Sanatorio de la Cañada
Sanford Health
Sanford Health - Marshfield Clinic
Science 37
Science Connections
Selene Clinical Research
Sensorium Clinical Research
Sigal SMS GmbH
Site Founder
South Broward Research
South Florida Clinical Research Institute
Southwest Family Medicine Associates
Spotlight Research Center
Sterling Research Group
StrideCare
Stryde Research
STUART ONCOLOGY ASSOCIATES PA
Sun Research Institute
Sun Valley Research Center/LICR/SOS
Suncoast Research Associates
Sundara Research
Suraya Group
Tarsadia
TDDA Specialty Research
TECHNOLOGICAL HEALTH SERVICES EIRL
Tekton Research
Tellabio International Research Services
Ten20Clinical Research
Terraqueo SMO
Texas Heart and Vascular Research Consultants
Texas Valley Clinical Research
The IMA Group
Total Research Group
TrialMed
Tribe Clinical Research
Troy Internal Medicine Research
TrueBlue Clinical Research
Ultimate Research Institute
United Research Institute
University of Chicago
University of Nebraska Medical Center
University of Washington
Urology Nevada
Valley Institute of Primary Clinical Research Group
Vantage Clinical Trials
Velocity Clinical Research
Vitalis Clinical Research Center
VM ClinTrials
Wake Forest University School of Medicine
Wellness Research Center
West Clinical Research

LOOKING AHEAD

Breakout Sessions I, II, & III

Networking Breaks

ThermoFisher SCIENTIFIC

Eagle Awards Gala



ADVARRA

Site Appreciation Reception

parexel



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CLINICAL RESEARCH FOR ALL


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