The Nucleus
Fall/Winter 2016

Huntington's Disease Society of America
Northern California Chapter

Life with HD – Marna and George Parks

By Richard Hackenberg

They met on Christmas Day 1947 while Christmas Caroling with a Presbyterian Youth Group in Tacoma Park, Maryland. They were in high school and George tried to date Marna for nearly18 months.

Finally, on their first date they went to see a film version of Gilbert and Sullivan's The Mikado. They saw each other during college. Marna went to the University of Maryland and National Art School in Washington D.C. She paints pictures and teaches porcelain painting. Her flower plates are stunning.

They decided to marry on the day George graduated from the United States Naval Academy in June 1954. He was first in his class as Academic Leader and a company commander. But, he opted for the Air Force to avoid sea duty so he could be with Marna. They did go to sea, however, sailing Chesapeake Bay in a 28-foot sloop on their honeymoon.

Appointed to the Naval Academy by California Senator William Knowland, George had the good fortune to meet two of America's greatest aviation heroes. As a passenger on a military flight from Alameda Naval Air Station to Chicago Midway his fellow passenger was General James "Jimmy" Doolittle, leader of the dramatic June 1943 B-25 bombing raid on Tokyo.

Then, in his senior year George was invited to attend a meeting with a delegation of Generals from Washington D.C. seeking input for the location of a new United States Air Force Academy. At that meeting he met General Charles Lindbergh, a member of the committee.

Although opting for the Air Force, George had three memorable Summer Cruises while at the Naval Academy: Copenhagen and Rotterdam in the heavy cruiser

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HDSA National Convention Upbeat; Offers New Hope for Tomorrow

By Richard Hackenberg

Baltimore, MD, Hyatt Regency Inner Harbor, June 2-4 -- The HDSA National Convention was an experiential paradox: the heartbreak of the HD families and the excitement of amazing progress by the MDs and PhDs. Overall, it was an uplifting three days, reinforcing ***Help for Today and Hope for Tomorrow.*** While no one stepped up with a forecast, it looks to me that Huntingtin gene lowering or gene silencing is likely to happen soon, probably within the next ten years.

Friday, June 3, 2016—
Convention Day One

Many excellent presentations are available on the HDSA website (link below.) My focus was on the Research Track so I will hit some of the highlights from my experience at general and research sessions.

http://hdsa.org/about-hdsa/annual-convention/2016-convention/

The Friday morning general session featured Career Caregiver Peter Rosenberger, who spoke about ***Hope for the Caregiver***, based on 30 years caring for his wife who was badly injured in an auto accident. He offered good advice

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USS Albany (CA-123); Halifax in the aircraft carrier USS Midway (CV-41), now the USS Midway Museum in San Diego; Rio de Janeiro aboard the battleship USS Missouri (BB-63), now the USS Missouri Memorial in Pearl Harbor.

As it turned out, the Doolittle meeting was prophetic when George earned his wings in a B-25 flying out of Goodfellow Air Force Base, San Angelo, Texas. After getting his wings he was asked to stay on as a flight instructor. During the next 21 years, he, Marna and their growing family of five children were assigned to Air Force bases in the US and Turkey.

In addition to Goodfellow, they were stationed at Marana AFB, Tucson, AZ; Wright-Patterson AFB, Dayton OH; Andrews and Bolling AFBs in Washington, D.C. while he studied the Turkish language at the Foreign Services Institute prior to assignment as Assistant Military Attaché at the US Embassy, Ankara Turkey. Additionally, George was Deputy Base Commander, Kusan South Korea, a one- year tour without family.

During his career he flew six multi-engine aircraft—B-25, C-45, C-47, T-29 (Convair Trainer), C-130 and C-141 flying more than 5000 hours. In Turkey, on his last C-47 flight he took Peace Corps Director Sargent Shriver and his Press Secretary Bill Moyers on a tour of Peace Corps sites.

In 1958, the Air Force sent him to Stanford for his Masters Degree in

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Convention Continued

and was very amusing. You can see some of his videos online-- http://caregiverswithhope.com/

Demystifying Clinical Trials: What's it like and why to they need ME. Moderated by HD Speaker Jimmy Pollard with George Yohrling of HDSA, Stacey Barton, SW and Jeanette Garcia, HD Volunteer, this session gave good reasons to participate in Clinical and Observational studies to advance the considerable progress in research. Participants get access, extra care and hope; help to advance science, fight HD; and are agents of change.

All family members should consider ENROLL HD: https://www.enroll-hd.org/

The typical participation process—contact, consent, clinical or observational studies, screening, baseline, follow-up, end. Best resource is HD Trialfinder https://platform.emergingmed.com/find-clinical-trials/hdsa#partnerhome

After lunch at which I met the newest HDSA Trustee Michael Berman and his wife Jocelyn Topper who just funded at scientific fellowship for a bright young neurologist to who wants to join the fight against HD, I attended: ***Ask The Scientists…Anything!*** Featuring HD Buzz founders Ed Wild, MD, PhD and Jeff Carroll, PhD, this completely interactive session was one of the best.

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President's Corner

By Richard Hackenberg

HDSA Convention: Hope is in the Air!

Get the latest info on HD Buzz; Use HD Trialfinder to join ENROLL-HD

The 31st annual HDSA National Convention at the Hyatt Regency in Baltimore, MD, June 2-4, 2016, was an experiential paradox: the heartbreak of the HD families and the excitement of amazing research progress by the MDs and PhDs.

When my late wife Mary was diagnosed HD positive in 2010. The outlook was bleak as there seemed to be little hope for any solution. Today progress in research is moving more rapidly than any other time since the gene was identified in 1993.

There are 12 initiatives in Phase III Clinical Development including the dynamic IONIS/Roche Antisense Oligonucleotide (ASO) Huntingtin lowering trial to be completed in 2017. And, there are several stem cell and immune system trails to treat physical symptoms, and to slow or stop the gene mutation

We were updated on the ***HD Human Biology Project*** in which six scientists around the world are working to better understand the biology of HD as it occurs in people. This is critical work as the disease only affects humans.

Additionally, HDSA has launched a new grant program in

President's Corner Continued…

The Parks Continued

Electrical Engineering, and he was attached to Hamilton Field for flight duty, showing up two months early to catch the summer session and completing his degree in one year. He was stationed at Travis AFB from 1965 until 1975, as a squadron pilot and C-141 flight examiner in the 22nd Air Wing.

After retiring in 1975, George used the GI Bill to earn his Double-E PhD at UCDavis, and remained part of the Travis AFB community. Marna typed his dissertation. He became Assistant Professor and later a full Professor at the Maritime Academy in Vallejo (now known as Cal State Maritime) where he taught for 16 years also serving as President of the Faculty Association.

While at the Maritime Academy, he went to sea once more aboard the training ship TS Golden Bear to participate in Expo86, commemorating Vancouver Canada's Centennial, the last world's fair in North America.

In September 2012 at age 80, George was diagnosed with HD. It was a complete surprise as they were unaware of any family history. At risk are their five children, 18 grandchildren, ages 5-32, and 12 great grandchildren. He has significant chorea, but, thankfully, his decision-making skills, short and long-term memory are good.

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Convention Continued

They also did a Saturday general session: ***The Best Time to Plant a Tree—A Global Research Update.*** If you only watch one video presentation, make it this one-- http://hdsa.org/about-hdsa/annual-convention/2016-convention/

The National Youth Alliance (NYA) Talent Show Friday evening was delightful, and raised significant funding to support NYA convention scholarships. Young people from 10-22 sang, danced, and participated in a dance auction for the Saturday night gala. HDSA Board Chair Jang-Ho Cha sang, played the piano and did a mock striptease while being auctioned.

Saturday, June 4, 2016—
Convention Day Two

Excellent ***Research Forum*** presentations by Walter Koroshetz, MD, Director of National Institute for Neurological Disease and Strokes (NINDS) who spoke about ***NIH and the American Taxpayers Investment in Neuroscience***, and Robert Pacifici, PhD, who spoke about ***Accelerating Therapeutics for HD: An Overview of CHDI's Portfolio & Progress.*** Don't miss Robert Pacifici. Both presentations: http://hdsa.org/about-hdsa/annual-convention/2016-convention/

At the ***HD Clinical Trials Showcase & Luncheon*** we heard about the Amaryllis

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President's Corner Continued

its Research Portfolio—The Berman-Topper Family Career Development Fellowship. The first award is to a scientist at Massachusetts General Hospital/Harvard Medical School who is working on the "Identification of genetic modifiers of somatic CAG instability in HD by vivo CRISPER-cas9 genome editing."

While we continue to provide Help for Today, our HIGH HOPES for tomorrow depend on you. Progress requires patient and family participation.

One relatively simple, yet important, way to help is to join **ENROLL- HD**. This worldwide study is for those who are HD positive and their families. You can enroll at UCDMC or UCSF. Questions? -- https://www.enroll-hd.org/learn/enroll-hd-faq/. And your go-to resource is www.HDSA.org .

Another way to participate is to volunteer to help at chapter fundraising events like the annual **Team Hope Walk—Sacramento**, or to consider joining the Chapter Board of Directors. We hope that you and your friends will contribute to our **Fall Research Appeal** that will be in your mail in the next week or two.

Overall the annual convention was an uplifting, optimistic three days. I was impressed and glad I attended. Consider the 2017 Convention in the Chicago area. HDSA offers scholarships to first time attendees.

The Parks Continued

He and Marna have donated significantly to the HDSA Northern California Chapter, designating their contributions to ongoing research. They are hopeful for a cure should any grand and great-grand children become symptomatic. At least two of their children are HD positive.

In 2015, the HDSA Northern California Chapter established The George and Marna Parks Award given annually to the individual, group or organization that has made a major difference in providing HD Help for Today (education and family services) and/or Hope for Tomorrow (research to find a cure.)

(Note: This is the first in a Life With HD Series. The editor thanks Marna and George Parks for their willingness to share their family story, and for their on-going support of HDSA Research.)

Convention Continued

Study, Legato-HD, Pride-HD, Enroll-HD, IONIS HTTRx gene silencing, AZEVAN and Vaccinex. You can find these listed in the HD Trialfinder.

After lunch I went to ***Meet HDSA's Board of Trustees,*** and asked if there is any correlation between Centers of Excellence and Chapters as we have three COE's in Northern California UCD, UCSF and Stanford. There is none, but in other conversations it looks like a Bay Area Affiliate might be started in 2017.

My final sessions were ***Exercises and HD*** with Chris Lamb PT and ***Why is HD Still Diagnosed as a Motor Disease*** with Christopher Ross, MD, PhD and Samuel Frank, MD. The exercises were mostly about Yoga and balance. HD as a motor disease diagnosis stems largely from first symptoms often being motor related, but there is a proposal to change the diagnosis protocol to Pre-Manifest HD and Manifest HD.

Winemaker's Dinner Honoring Dawn Doster

By Richard Hackenberg

In recognition of her four years as President of the HDSA Northern California Chapter Dawn Doster receives the HDSA Leadership Award from current president Richard Hackenberg.

Currently serving as HDSA Northern California Board Vice President after four years as Board President, Dawn Doster demonstrates the "help/hope" spirit that makes HDSA the most effective organization in the fight against Huntington's disease.

Since her daughter was diagnosed with HD, Dawn has been on a mission to do everything she can to provide help and to improve the quality of life for HD families in Northern California.

Shortly after joining the Board, she took the president's and did wonders for fundraising, board development and family services. Her MBA and government contract work experience were evident in her work.

In Fundraising, her leadership produced results 3 times that of the prior four years. She almost single handedly organized a successful golf tournament, and played a key role in managing the annual TEAM HOPE WALK—Sacramento.

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Doster Continued

With her VP Les Pue she recruited seven new members including former and current Board Treasurers, a major donor and the current President. The Chapter received the HDSA 2015 Outstanding Board Development Award.

Dawn has played a key role at the annual Chapter Convention presenting the HDSA story and family service opportunities to HD families. She developed excellent relationships with Kaiser Permanente, and HDSA Centers Of Excellence at UCDMC, UCSF and Stanford.

She is an active participant in the Sacramento support group, and with her husband Ron stepped up to lead the group when social worker Lisa Kjer Mooney took maternity leave.

And, Dawn has done all this while recovering from a severe shoulder injury. Like Marjorie Guthrie before her, Dawn Doster, who lives in Sacramento, but hails from Georgia, is a strong leader, and a “steel magnolia” for HD.

Resources for HD Families

Information/Research

•HDSA Research-- http://hdsa.org/hd-research/a-leader-in-global-hd-research/

•Enroll-HD-- https://www.enroll-hd.org/learn/about-hd/?enrollsid=43be5528e3e364de124a0d460afb7bc1

•HDSA Webinars-- http://hdsa.org/hd-research/hd-research-webinar-series/

•Clinical Trials-- http://hdsa.org/hd-research/enroll-in-a-clinical-trial/

•Huntington’s Study Group-- https://hdinsights.org/

•HD Buzz-- www.hdbuzz.net

•National Youth Alliance-- http://nya.hdsa.org/

•YouTube Videos-- https://www.youtube.com/channel/UCbjowsMQBkoj8TJbjsxPdaw

•Heredity Disease Foundation—www.hdfoundation.org

HDSA Centers of Excellence in Northern California

•UC Davis Huntington’s Disease Center of Excellence

•Alexandra Nelson, MD, PhD | UCSF Memory and Aging Center

•Stanford Center of Excellence/Huntington’s Outreach Project for Education at Stanford http://hopes.stanford.edu/

Documentaries

•The Lion's Mouth Opens (2014) http://www.hbo.com/documentaries/the-lions-mouth-opens

•https://vimeo.com/ondemand/amindinquicksand

•http://twitchdocumentary.com/

•http://aliveandwellthefilm.com/

•http://www.doyoureallywanttoknowfilm.com/

•http://www.wehaveaface.org/#!documentaryinformation/chqk (The Huntington’s Disease Project Removing the Mask—2015)

Amazon Smile Charity Program

•https://smile.amazon.com/ch/22-2942362

•0.05% of price of eligible purchases will go to the Chapter

Update: Kaiser Permanente Genetic Movement Disorder Clinic - A partner UCDMC HD Center of Excellence

By Mara Sifry-Platt, MS, LCGC-Genetic Counselor

The Genetic Movement Disorder Clinic at Kaiser Permanente in Sacramento has been caring for people with hereditary movement disorders since 2005, and received recognition as an HDSA Center of Excellence in partnership with UC Davis in 2014.

The multi-specialty clinic includes professionals with expertise in Huntington’s

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Kaiser Continued

disease providing comprehensive care for patients and families. Members of Kaiser Permanente from all over Northern CA are welcome to attend the clinic, usually held monthly. For those that have to travel to see us, the clinic will consult with local care providers to minimize travel needs.

Team members at Kaiser:
Dr. Suketu Khandhar-Movement Disorder Neurologist
Drs. Mark Lipson, Kamer Tezcan, and Billur Moghaddam-Geneticists
Drs. Brad Briercheck and Julie Hylton-Psychiatrists
Drs. Rich Friedrich, Brian Masselink, and Gregg Nelson-Pediatric Neurology Elle Tadina-Siau, MSW-Medical Social Worker
Suzanne Trygar, LCSW-Palliative Care Social Worker
Jeanine Perry, PT-Physical Therapist
Karen Brookhyser, MS, LCGC, Cassie Farrar, MS, LCGC, Katie Jones, MS, LCGC, and Mara Sifry-Platt, MS, LCGC-Genetic Counselors

The integrated system at Kaiser Permanente can easily refer those in need to local physical, speech and occupational therapists, and other experts as appropriate.

The Clinic holds an annual HD Education Event open to the public. Membership in Kaiser Permanente medical insurance is not required. Those with movement disorders, family members, care givers, and support people are welcome to attend.

Presenters from Kaiser Permanente and UC Davis Medical Center will discuss important issues like medical management, behavior issues, resources, and a research update will be provided. There is no cost and parking is free.

The Movement Disorder team is honored that so many people trust KP for care and guidance on this difficult journey. They strive to help people with HD and their families live with courage, dignity, and grace.

For more information, contact:
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DNA Direct – A Family Update

By Andrea Zanko, MS LCGC

The Marin Support group has been meeting since 1993 – we often wonder if we are the oldest group in existence on the planet!

Our group changes with the tides – sometimes there are only 3 – 4 people at the table and other times there are 20! Some of us have been participating for many years - and we welcome newcomers with open hearts and arms. Stories are shared while we laugh and cry - and sometimes we get angry and feel frustration - and we experience joy and hope – likely all in the same evening!

Lately we have been working more on mindful living with gratitude. **NOW** is our best moment – and we think of ways to contribute and express thanks for what we do have – even if 'only for today.'

We have our **REACH** list (**R**espond-**E**mpathy-**A**ttitude-**C**ompassion-**H**ope) or (**R**espect – **E**nhance – **A**ction – **C**are – **H**umor) – a list of our names, emails and phone numbers so that if one is feeling alone there is another person to whom you can reach.

We follow 'Council Circle' guidelines, with intentions to

- Speak from the heart
- Listen from the heart
- Speak spontaneously
- Speak leanly
- Remember privacy

Our group is made up of delightful, sensitive people who truly care. We try to share helpful information and offer unconditional, nonjudgmental support--23 years and going strong!

Thoughts About Living

Thoughts About Living
For Huntington's Families.
Please consider these--

Practice **Mindfulness:**
Relax, enjoy the Present.
Don't **Rehash** the Past.
And don't **Rehearse** the Future.
You'll live Happier, Longer

And, please don't forget
To **count your blessings** daily.
If we're all grateful
The Gratitude Effect will
Get us through the toughest times.

And, a way-of-life poem—

I slept and dreamt life was joy.
I awoke and saw that life was service.
I acted and behold service was joy!
--Rabindranath Tagore

Honorariums & Memorials

The Northern California Chapter has only been able to provide services such as eight support groups, funding for cutting edge research, as well as informative conventions with the generous support and donations from Northern California and beyond. It is with great honor and respect that we continue to say thank you for all of the donations that we continue to receive.

Les Pue in memory of Margaret Pue ~•~ Les Pue in honor of Dawn Doster ~•~ Bonnie L. Richards in honor of Cheri Harries & Penny McMasters ~•~ Louise Freeman in memory of Bob Nelson ~•~ Barbie Burke in memory of Tim Roberson and in honor of Judy Roberson ~•~ The Mcclary Trust Irrevocable in memory of Neil Taylor ~•~ Meredith Moody in memory of O.J., Mark, Matthew McAtee ~•~ Margarita Molina in honor of Nelly Molina ~•~ Nora McGuinness in honor of Vicki Wheelock, UC Davis Center of Excellence ~•~ Eleanor Lefferts in memory of William L. Williams ~•~ Pamela and James Self in memory of Herbert Hilard and Louis Fusaro and in honor of Jan Hunter ~•~ Dewey Demartini in honor of Alma Swisher ~•~ Koaki B. Harris in memory of Edward W. Bailey & Karen E.N. Bailey

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Find more information about us on our website:
http://northernca.hdsa.org/

The Nucleus is the HDSA Northern California Newsletter, published biannually: Spring/Summer & Fall/Winter. For questions and comments please send an email to nothernca@hdsavolunteer.org.