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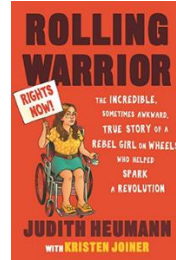
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- Robert Levy
- Paul Mansell
- Wesley Witherspoon
- Lisa Cooley
- Goldie House

Remembering the Life and Legacy of Judith Ellen Heumann 1947-2023

By **Robert Levy**, UC Davis MIND Institute UCEDD SSAN Representative



The late Self-Advocate Judith Ellen Heumann was born on Thursday December 18, 1947, in Philadelphia, Pennsylvania. She was an American disability rights activist, known as the "Mother of the Disability Rights Movement." She was recognized internationally as a leader in the disability community. Heumann was a lifelong civil rights advocate for people with disabilities. Her work with governments and non-governmental organizations (NGOs), non-profits, and various other disability interest groups, produced significant contributions since the 1970s to the development of human rights legislation and policies benefiting children and adults with disabilities.

In June of 1949 Judy was diagnosed with Polio, which impacted her mobility and presented a number of access issues for the rest of her life. Judy grew up in Brooklyn, New York and had a determination not to give up on life. She made the best of it by being a self-advocate for the remainder of her life. She rejected cliches about disability as a tragic experience, saying, "Disability only becomes a tragedy for me when society fails to provide the things, we need to lead our lives – job opportunities or barrier-free buildings, for example. It is not a tragedy to me that I'm living in a wheelchair".

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Judith Heumann and her parents had to fight repeatedly for her to be included in the educational system. The local public school refused to allow her to attend, calling her a fire hazard because of her wheelchair, which wasn't right.

In 2020 Judith Heumann appeared in a documentary called *Crip Camp* which it was about [Camp Jened](#), a summer camp in New York described as a "loose, free-spirited camp designed for teens with disabilities." The film features Larry Allison, [Judith Heumann](#), James LeBrecht, Denise Sherer Jacobson, and Stephen Hofmann, and focuses on campers who turned themselves into activists for the [disability rights movement](#) and follows their fight for accessibility legislation.

In 1992 she got married to Jorge Pineda, and last year they celebrated their 30th wedding anniversary. In 1993 they moved to Washington DC where she lived for remainder of her life. Judith was an international self-advocate too and has given numerous speeches, talks, and interviews.

On Saturday, March 4, 2023, in the afternoon Judith Ellen Heumann passed away at the age of 75 years and 76 days. The following Monday, March 6, news stations like NPR reported about her passing and impact on the Disability Rights Movement. A funeral was held for her on March 8th over Zoom. There were a lot of people throughout the world who attended and celebrated her life over Zoom. She left our world, and she will always be remembered for all the work that she has done, and she will be missed.

There is always going to be a need for self-advocacy. We still need to make even more improvements for our society in order for all people to have a productive life, just like anyone else who doesn't have a disability. People with disabilities should be treated equally and should never be segregated in our society again. Here are a few helpful links to articles remembering Judith Heumann and resources about her impact on the disability community:

- Here are a few videos about Judith Heumann:
 - [Our fight for disability rights -- and why we're not done yet | Judith Heumann TedTalk](#)
 - [Daily Show Interview March 2020](#)
 - [MSNBC Remembers Judy Heumann](#)
- Here are a few websites about Judith Heumann:
 - <https://judithheumann.com/>
 - [Disability Scoop Remembers Judith Heumann](#)
 - [Mobility International USA Remembers Judith Heumann](#)



Resiliency

By Paul Mansell, San Diego Regional SSAN Representative

A number of failures, setbacks, and frustrations stand out when I reflect on my life. I have failed academics, romance, career, home ownership, and credit card management. The list goes on and on. So, what enabled me to pull myself together and carry on and persist after I encountered these adversities? I can answer that in one word, resiliency.

What is resiliency? It is a character trait fundamental to one's well-being. It allows us to pick ourselves up after adversity has knocked us cold, flat onto the mat. It hurts when adversity punches us in the face, and we get confused and disoriented as we fall to the ground. Everything seems to be spinning and then fading to black. We hardly know what to do as we stagger with all our effort to pull ourselves up on our own two feet. Once we are on our two feet, the world stops spinning and gradually comes into focus.

That is what resiliency is like for me. To ease my pain, I tell myself it is better to try and fail than never try. That helps a little; it is a baby step in moving again. Each step is tentative and unsteady. As I take more steps, my footing becomes steadier, surer, and more confident. I wish that change happened overnight, but it may take days, weeks, and sometimes years to get back up to speed.

What sustains us during this time of transition? For some, it is faith in a higher power; for others, it's the support of family, friends, and peers. For some, it is pride or a cause. For many, it is necessary; I must do so because my family depends on me; whatever you use, bite your teeth, clench your fists, get up, and go.

Life is too precious and wonderful to stay sprawled out on the ground. Sure, it hurts, and hurts badly. You tell yourself you tried, gave it your all, and came up short. That is even more reason to pull yourself up and get up. Remember this; you are a unique individual. There will never be a person like you with your exact talents, abilities, sensibilities, and preferences. You also have a particular purpose in life that you alone can fill. So, suck it up, carry on, and walk on the pathway we call life and the journey to your destiny.

Recapping the California Statewide Self-Advocacy Conference

By Wesley Witherspoon, USC Children's Hospital UCEDD SSAN Representative



This year's [California Statewide Self-Advocacy Conference](#) was held on Friday, May 12 and Saturday, May 13, 2023. The theme for this year's conference was "Leaping Forward" and was the first time the conference was held in-person since the start of the pandemic. This year's conference was held at the Wyndham Sacramento (formerly the Crowne Plaza).

Daniel Meadows was the keynote speaker for day one of the conference and kicked things off by speaking about the importance of self-advocacy. He encouraged the crowd to speak up for themselves, and don't let others get in their way. This year's conference featured a number of sessions about self-determination, relationships, CalABLE, building friendships, Zumba, Regional Center services, self-advocacy, IHSS, and how to prepare for the end of your life.

I gave the keynote for the second day of the conference. My address focused on the importance of self-care and taking care of yourself when you are all alone. I shared my life story and my work to advocate for people with disabilities both in California and nationally.

Advocates from across California and Nevada attended the conference. There were over 200 people in attendance at this conference. Many people were happy to see each other after 3 years of COVID. Riana Hardin, Maria Marquez, Charles Nutt, and Lisa Cooley spoke about Self-Determination. Lisa Cooley spoke about In-Home Support Services. Lisa Cooley was also a part of the exhibit for Self-Determination. Kecia, Robert, and I also presented on COVID and our perspective UCEDDs.

I look forward seeing what sessions, information, and resources are shared at the 2024 California Statewide Self-Advocacy Conference. Keep a look out for information about the 2024 conference and consider applying to be a session presenter.



Summer Safety Tips

By **Eric Aguilar**, San Bernardino Regional SSAN Representative

As we head into the summer months, and the weather gets warmer, it is important to remember to take care of yourself and prepare for the higher temperatures. Here are some tips to help you stay cool:

1. Stay in an air-conditioned location as much as possible.
2. Drink plenty of fluids and water, even if you do not feel thirsty.
3. Take several breaks from the heat, especially midday when the sun is hottest.
4. Do indoor activities.
5. Wear loose, lightweight, light-colored clothing, and sunscreen. Remember that you should reapply sunscreen as indicated on the package.
6. Take cool showers or baths to cool down.
7. Check on friends or neighbors during extremely hot days and have someone do the same for you.
8. Never leave children or pets in cars.
9. Check the local news for health and safety updates.
10. Too much heat can lead to headaches, dizziness, and even nausea, vomiting, red clammy skin, not sweating, or stop sweating, or seizures

If you notice any of these symptoms, you should get out of the sun immediately and head indoors or to a shady spot. If available, a cool wet washcloth should be applied to their skin to help bring down their body temperature. To help prevent overheating make sure to drink plenty of water before, during, and after spending time outside. When planning outdoor events, keep in mind that the sun is at its hottest between 10am and 4pm, so having spots where individuals can go inside to cool down or seek some shade is vital.

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11. In light of COVID-19 and other public health concerns, try to keep at least 6 feet between yourself and others, and wear cloth face coverings, especially in crowded areas.
12. Utilize your local cooling centers in your city.
13. Use an umbrella for shade when walking or sitting in chairs.
14. Protect your eyes from the sun
15. Wear a hat with a brim

Here are some water safety tips for the pool and beach water:

1. Take swimming lessons if you do not know how to swim
2. Always use the buddy system when swimming: take a friend or partner with you
3. If you do not have a friend to go swimming with, ask someone nearby to watch you or swim with, or swim near a lifeguard
4. Lifeguards are there to help you. Make sure you listen to them and follow directions
5. Wear a life jacket (US Coast Guard approved)
6. Do not swim if there is lightning or stormy weather
7. WHEN IN THE POOL: Be careful of the deep end and stay where the water is not over your shoulders
8. WHEN AT THE BEACH: Watch for dangerous waves and fast-moving water
9. WHEN AT THE BEACH: Know the meaning of colored beach flags: RED = Danger YELLOW = Be careful when you swim, there is still danger in the water GREEN = Safe to swim, but be careful when swimming BLUE AND PURPLE = Sharks, jellyfish and other dangerous sea animals.
10. WHEN AT THE BEACH: Watch the weather before going into the water.



Celebrating the 33rd Anniversary of the Americans with Disabilities Act (ADA)

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative



July 26, 2023 will mark the 33rd anniversary of the signing of the [Americans with Disabilities \(ADA\)](#). The ADA was signed into law on Thursday July 26, 1990, by the late 41st US President George Herbert Walker Bush.

The ADA has opened doors and opportunities for people with disabilities because we are able to have better access to employment, transportation services, public spaces, and communication systems. People with disabilities are now able to go more places with the help of more accessible transportation services, that were not options for them before. This means that people with access and functional needs (AFN) are able to go to work and travel throughout their communities more freely, leading to their own independence thanks to adaptations on public transportation and the existence of curb cuts, ramps and accessible bathrooms.

The need for advocacy is never done, but it is important to celebrate advocacy and legislative achievements, so we know that we are making an impact. Thank you, all past or present self-advocates, for working on getting the ADA bill signed into law. Today people with disabilities are glad that we have ADA for community use. So, for ADA happy 33rd anniversary. For next year on to the 34th anniversary of ADA by continuing the self-advocacy work as a nation to keep on having a productive life for all people with disabilities throughout the nation.

SSAN Members

- Vacant – North Coast
- Charles Nutt – North State
- Lisa Cooley – Sacramento
- Ellen Sweigert – North Bay
- Regina Woodliff – Bay Area
- Robert Balderama – North Valley Hills
- David Forderer – Central Coast
- Rebecca Donabed – Sequoia
- Julie Gaona – Los Angeles
- Sean Sullivan – Orange County
- Eric Aguilar – San Bernardino
- Paul Mansell – San Diego Imperial
- Desiree Boykin – ARCA
- Goldie House – CFILC
- Nicole Patterson – DDS
- Scott Barron – DRC
- Robert Levy – UC Davis Mind Institute
- Kecia Weller – UCLA Tarjan Center
- Wesley Witherspoon – SCDD and USC Children’s Hospital
- Alex Reyes – SCDD



Healthy Relationships

By Wesley Witherspoon, USC Children’s Hospital UCEDD SSAN Representative



Relationships are important to us. It is good to have a healthy relationship with our friends, family, significant other, etc. However, there are relationships that are abusive. If you find yourself in an abusive relationship, it is ok to ask for help and remember that another person’s treatment of you is not your fault.

Here are some signs to help you to know if you are in an abusive or unhealthy relationship:

1. Your partner communicates harshly to you
2. You feel mistreated by your partner
3. Your partner makes untrue accusations to you
4. Your partner tries to control what you do or how you spend your money
5. Your partner isolates you from your friends and family
6. Your partner forces sexual activities on you or controls your reproductive choices
7. Manipulates children or dependents
8. You or your partner are non-communicative with each other
9. You and your partner don’t trust each other
10. There is a fight for control in the relationship
11. Your partner ignores your boundaries

These are just a few things to look out for if you are unsure of if your relationship is unhealthy.

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SSAN Mission Statement

The Statewide Self-Advocacy Network (SSAN) promotes leadership and builds bridges that strengthen advocacy among disability communities by focusing on policy change.

[SSAN’s past Newsletters, Annual Reports, and Meeting info](#), can be found at www.scdd.ca.gov under the “Self-Advocacy” tab

Let us know if you want to see anything specific in future newsletters!

How do you contact the SSAN Newsletter Editor Robert Levy? Leave a message for him by contacting the SCDD Self-Advocacy Coordinator **Riana Hardin at (916) 263-8196**

Check out the [SCDD YouTube Page](#) for stories from self-advocates, past meetings, and more!

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Here are some signs of a Healthy Relationship:

1. You and your partner communicate openly with each other
2. You and your partner respect each other
3. You trust each other
4. You are honest with each other
5. You see each other as equals
6. You set and understand each other's boundaries
7. You ask each other for consent
8. You support each other while parenting (children and pets)





SSAN Celebrates 11 Years of Advocacy

By Robert Levy, UC Davis MIND Institute UCEDD SSAN Representative



It is hard to believe that the Statewide Self-Advocacy Network (SSAN) has just turned 11 this year. Over the years SSAN has seen a lot of changes in who has been a member, and there have also been changes in the staff who support us.

We are lucky that some founding members are still a part of this awesome group and able to help guide newer members. SSAN meetings have given us a lot of information on programs, resources, and legislation being considered both in California and nationally. We have participated in calls for action and rallies.

As self-advocate leaders we work hard to make sure that the work that we do makes things better for ourselves, as well as others who have I/DD and help them to have productive lives.

Now that SSAN is heading for its 12th year, I look forward to working with staff and members of SSAN to keep doing the important work to improve the lives of people with I/DD, so they can feel included in their communities and have bright futures. Over the last year, we added a seat on SSAN for the Youth Organizing (YO!) Disabled and Proud to connect with and include youth with disabilities into our activities. Hopefully we will be able to continue to grow SSAN in the future, and develop more trainings to share with our communities. So, happy 11th birthday to SSAN! As we head into our 12th year: we will continue to advocate for ourselves and to make society better for people like us with disabilities to have a productive life.

Apply to be a Council Member for the California Behavioral Health Planning Council!

The California Behavioral Health Planning Council (CBHPC) has two (2) open positions for direct consumers to sit on their board and advise the agency on policies, programs and practices. The agency is looking for people with lived experiences of mental illness who are receiving or have received mental/behavioral health services in California. If you are interested, consider filling out the

[Online California Behavioral Health Planning Council Member Application](#)



Kudos Corner

By Goldie House, California Department of Developmental Services SSAN Representative

Let's give Eric Aguilar Kudos this month. He has been an advocate since 2019 by connecting with the State Council on Developmental Disabilities San Bernardino Regional Office Regional Advisory Committee (RAC) and other advocacy activities. When the opportunity opened up to represent San Bernardino as a member of SSAN last year, Eric saw the chance to continue his advocacy journey.

Eric puts together the skills, strategies, as well as other empowering tools, to educate individuals to be empowered and implement strategies to increase their self-advocacy.

Eric is so proud of the changes that have been accomplished for people with disabilities through advocacy. Advances in technology have opened-up a lot of opportunities for Eric since the start of COVID-19. The ability to take access and functional needs (AFN) trainings and certification courses online has allowed Eric to expand his leadership skills and knowledge of emergency management. Eric is passionate about ensuring that people with disabilities receive emergency preparedness and making sure that first responders and crisis management teams consider accessibility in the planning process. Eric is currently a member of the CAL OES planning and preparedness working group and serving as vice chair of the San Bernardino Regional Advisory Committee. Eric joined Statewide Self-Advocacy Network (SSAN) in 2022 and set to work sharing his knowledge of emergency preparedness by sharing tips in the March 2023 newsletter. Eric will also be working on emergency preparedness lectures for SSAN.

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At the beginning of COVID-19 Eric successfully completed 3 days of the Disability and Access and Functional Needs, (DAFN) Toolboxes Train the Trainer Academy. Eric had just finished completing the (DAFN) workshop. Eric has been on a journey to transform advocacy and has had a great start. Eric is grateful to be a member of a supportive group like the Statewide Self-Advocacy Network (SSAN) that has helped to him be proactive with learned skills and strategies of self-advocacy. Eric has made great impact at the San Bernardino Regional Office of State Council Developmental (SCDD) for being a positive team player and is participating in the Inland Empire Autism Society (IEAS). “Through my Mentorship of State Council Developmental Disabilities (SCDD), I have Found a passion for teaching and was selected to join the CAL OES planning and preparedness working group”.

As an individual with a disability, Eric has conquered numerous obstacles. He is grateful that nobody gave up on him growing up, even though he has a disability. This encouraged him to not give up on himself and got him interested in helping others through teaching and advocating. He wanted to give back to people with disabilities.

Eric enjoys inspiring people through his advocacy and giving back to disability communities. He likes the camaraderie he has with other people or groups with disabilities, and says we’re like the Marvel Avengers or the Justice League, or the X-men from all over the world.

For the dedication and resilience of strengthening advocacy, we give kudos to Eric Aguilar and we look forward to seeing his continued personal growth.



Good News Corner

Here are some examples of websites that you can find uplifting news:

- [The Good News Network: California](#) for up-to-date information about interesting positive things that are happening
- [Positive News](#) is a site that you can check out to see what is happening around the world that is positive
- [Good Good Good](#) shares really good news, not just feel-good news
- [Happy News](#) celebrates all that is good in the world
- [Optimist Daily](#) is a site that shares solutions and good news from around the world

Disability-Related Reads and Podcasts

Here are a few Self-Advocacy and Disability-related publications to check out:



[Lawmakers Work to Improve Air Travel on Disability Scoop](#) through SB 1459 and other bills. [Disability Scoop](#) is an online resource with disability-related news



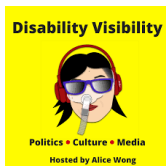
[Social Security Administration Blog](#) has SSI information



[World Institute on Disability News](#) has updates on what is happening around the world



[RespectAbility News](#) has updates on national efforts to engage people with disabilities in the political process



Learn About SSAN Member Organizations

- [Association of Regional Center Agencies](#)
- [California Foundation for Independent Living Centers](#)
- [Department of Developmental Services](#)
- [Disability Rights California](#)
- [University of California, Davis MIND Institute](#)
- [University of California, Los Angeles, Tarjan Center](#)
- [University of Southern California, Children's Hospital](#)

Self-Determination Update

Self-Determination is LIVE in California. Check out the [DDS Self-Determination Newsletter](#) for the latest on California's Self-Determination Program. Talk to your service coordinator to learn more.



Tips for Staying Positive in Trying Times

There is so much happening in our communities right now and at times it can feel over whelming. Here are some tips for keeping calm that we want to share with you:

- Remember your ABC's: Always Be Caring
- Listen to music: your favorite artist, or type of music
- Have a dance party and move around
- Try boxing or Thai Chi
- Talk to a friend or family member
- Mentor another advocate
- Write about how you are feeling or thinking
- Read and learn something new
- Go for a walk or jog outside: fresh air is good for you
- Check out a coffee/tea shop and people watch
- Volunteer for an issue that you care about
- Share your story/experiences with others
- Get plenty of rest to feel energized for the next day
- Try to eat healthy
- Practice Yoga/stretching or mindful meditation
- Know that you are not alone
- Stay involved in your community by joining a board

Community Resources

[SARTAC Zoom Meetings](#)

[ARCA Regional Center COVID-19 Resources](#)

[DRC's Build Back Better Resources](#)

[SSA Ticket to Work Tips to Open Your ABLÉ Account](#)

[Office of Self-Determination Ombudsperson](#)

[US Dept Of Education Office of Civil Rights Digital Access Series](#)

[How to Talk about Disability Sensitivity](#)

[20 Ways to Boost Your Mood from Tips for Success](#)

SAVE THE DATES

Disability Rights California



[Events and Trainings](#)

CalABLE



[News and Trainings](#)



[DO Network Training Library](#)

Plain Language COVID-19 Resources Available on: [SCDD Website](#)

Register for the Monthly California Statewide Self-Advocacy Chats on Zoom



[Current Issues and Resources](#)

[Voting Resources](#)

**DRC Voting Hotline:
888-569-7955**

[Disability Vote California](#)

Have questions about the Self-Determination Program? [The Self-Determination Advocates Leadership Group](#) meets monthly on Zoom



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