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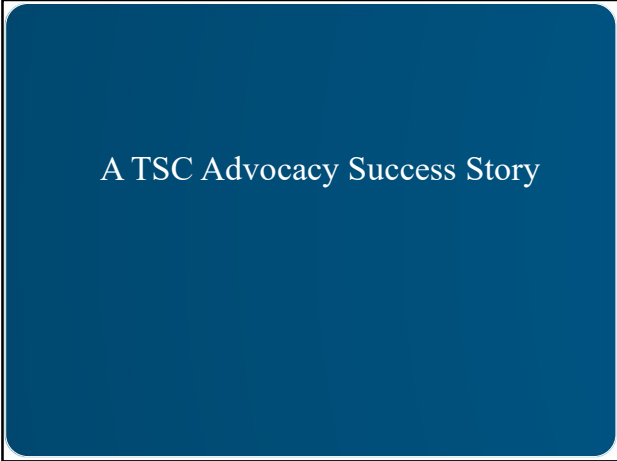
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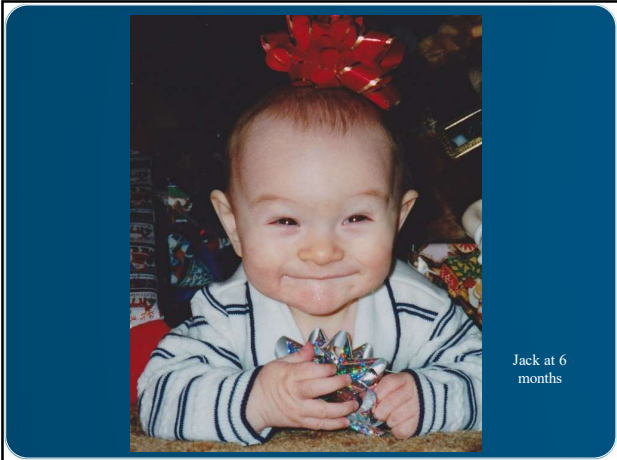
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Dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected.



[www.TSCalliance.org](http://www.TSCalliance.org)

“Hope, No Matter How Complex.”

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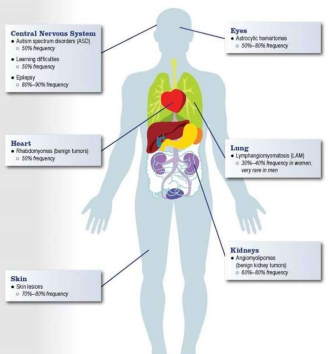
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### Tuberous Sclerosis Complex (TSC)

**85%**  
OF PEOPLE WITH TSC EXPERIENCE SEIZURES, OF WHICH 40% HAVE INTRACTABLE EPILEPSY.

Autism occurs in about **50%** of people with TSC.

#### TSC Clinical Manifestations



**Central Nervous System**

- Autism spectrum disorders (ASD) - 30% frequency
- Learning difficulties - 40% frequency
- Epilepsy - 80%-90% frequency

**Heart**

- Rhabdomyoma benign tumor - 50% frequency

**Skin**

- Shagreen patches - 90%-95% frequency

**Eyes**

- Astrocytic hamartomas - 20%-40% frequency

**Lung**

- Lymphangioleiomyomatosis (LAM) - 20%-40% frequency in women, very rare in men

**Kidneys**

- Angiomyolipoma benign kidney tumor - 60%-80% frequency

TSCRP funding has supported research in these clinical manifestations, some of

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## Advocacy Wins!

1. Research and Reach Out

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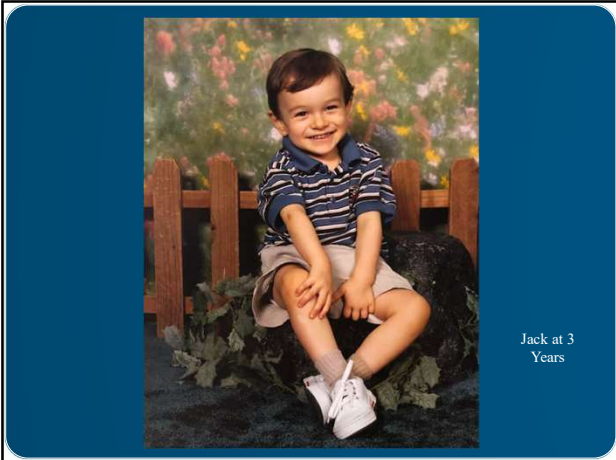
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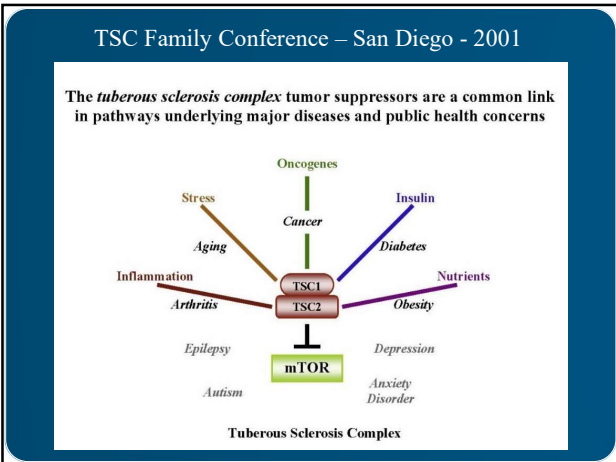
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## Advocacy Wins!

1. Research and Reach Out
2. Be Brave; Do what you feel is right
3. Attend Conferences, Educational Events

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First World TSC Conference,  
July 2014!



**NOVARTIS**  
TITLE SPONSOR

CONNECT  
CELEBRATE CONQUER

2014 WORLD TSC CONFERENCE  
July 3-6, 2014 • Washington, DC

PRESENTED BY  
**THE ROTHBERG INSTITUTE**  
For childhood diseases



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Second World  
TSC  
Conference,  
July 2018!



2018 WORLD TSC CONFERENCE  
KNOWLEDGE  
INSPIRATION  
UNITY

EMPOWERING THE  
GLOBAL TSC COMMUNITY

DALLAS, TX • JULY 26-29, 2018

Tuberous Sclerosis Alliance

TSCI Tuberous Sclerosis Complex International  
A Worldwide Organization of Tuberous Sclerosis Complex Associations

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Third  
World TSC  
Conference,  
July 2022!



TITLE SPONSOR **Jazz Pharmaceuticals**

hopefulrelentlessstrong  
**TOGETHER**

2022 World TSC Conference  
JULY 28-31, 2022 • DALLAS, TEXAS

PRESENTING SPONSOR **Nobelpharma**

CO-HOSTED BY

**TSC Alliance**

TSCI Tuberous Sclerosis Complex International

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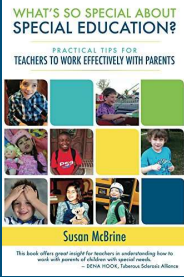
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**Susan McBrine**

Author, Special Education Advocate, Teacher, Mother

Four Mothers Began the TSC Alliance in 1974

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**Advocacy Wins!**

1. Research and Reach Out
2. Be Brave; Do what you feel is right
3. Attend Conferences, Educational Events
4. Tell Your Story; Present Your Ideas

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**A Dedicated Grandfather – Will Cooper**






Advocated such that a new research program was created and funded

First \$1 Million approved in 2001

**TSCR**



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Annual March on the Hill in 2018

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TSC Advocacy and Research - Helping Families

Billy, our youngest TSC Advocate at the annual March on the Hill in 2018

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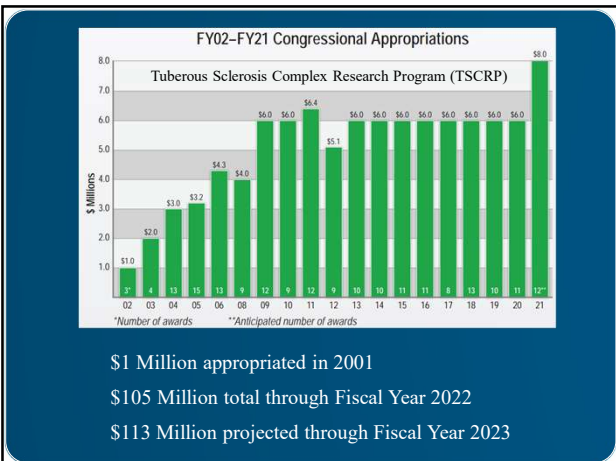
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TSC Progress – Building on Discoveries

- Medications that reduce tumors without invasive surgery

2008 tumors prior to everolimus      2013 tumors significantly reduced

Permission to use these images was given to me by his mother at the World TSC Conference in Dallas, Texas, July 2018

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TSC Progress – Preventing Epilepsy in Infants

International TSC Consensus Guidelines: Still to Come

Can early detection and pre-emptive treatment with vigabatrin prevent epilepsy and developmental delays in TSC?

Can early treatment with everolimus prevent epilepsy and developmental delays in TSC?

EPISTop PREVENT TSCure STOP 1 TSCure STOP 2

Infant EEG and Seizure Studies

EPISTop Prevention of epileptogenesis in EPISTop study

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There are now four (4) FDA approved treatments in the United States available for some aspects of TSC or related conditions.

These approved options are:

- Afinitor® (everolimus), (Shrink Tumors)
- Rapamune® (sirolimus), (Shrink Tumors)
- Sabril®, Vigadrone® (vigabatrin), (Infantile Spasm Seizures)
- Epidiolex® (cannabidiol); (Seizures)

Shrink or Prevent Tumors  
Reduce or Stop Seizures

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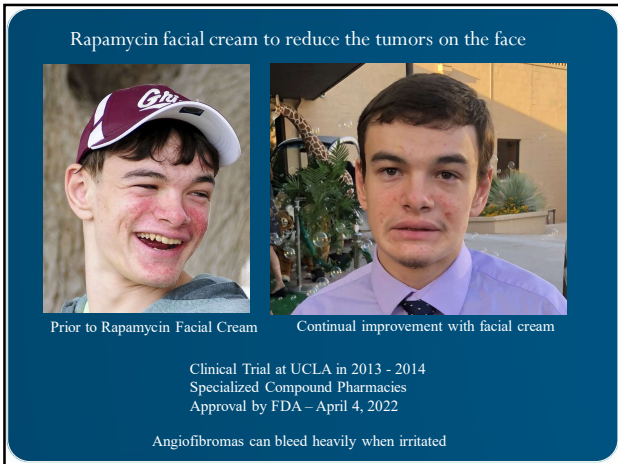
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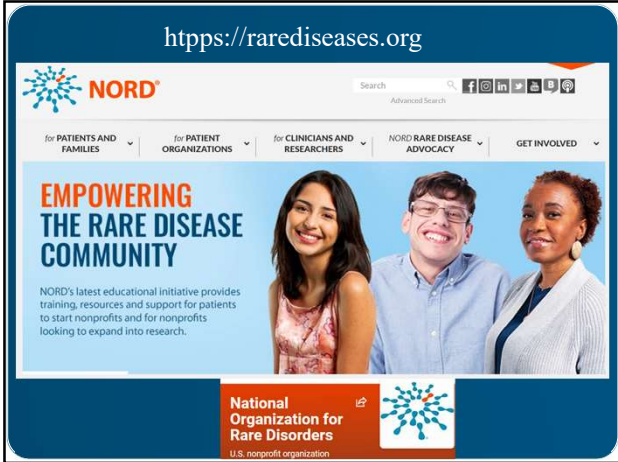
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# Polypharmacy

**pol·y·phar·ma·cy**

[ˌpɑliə ˈfɑrməsi]

NOUN

the simultaneous use of multiple drugs to treat a single ailment or condition.

- the simultaneous use of multiple drugs by a single patient, for one or more conditions.

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**Dr. Tanjala Gipson**

TSC Center of Excellence at Le Bonheur Children's Hospital

Memphis Tennessee



**Dr. Rajsekar (Raj) Rajaraman**

TSC Center of Excellence at UCLA

Los Angeles California

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# Telehealth

**What does telehealth mean?**

Telehealth – sometimes called telemedicine – lets your health care provider provide care for you without an in-person office visit. Telehealth is done primarily online with internet access on your computer, tablet, or smartphone.

There are several options for telehealth care:

- **Talk to your health care provider live** over the phone or video chat.
- **Send and receive messages** from your health care provider using secure messaging, email, secure messaging, and secure file exchange.
- **Use remote monitoring** so your health care provider can check on you at home. For example, you might use a device to gather vital signs or other vitals to help your health care provider stay informed on your progress.

[What is telehealth? | Telehealth.HHS.gov](https://www.hhs.gov/telehealth)

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### Advocacy Wins!

1. Research and Reach Out
2. Be Brave; Do what you feel is right
3. Attend Conferences, Educational Events
4. Tell Your Story; Present Your Ideas
5. Volunteer
6. Find and Engage the Experts

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“Thank you so much for the literature.

This told me more in this book than the last 3 months of us trying to find any help.”

From a grateful grandmother of a lovely infant, who has TSC.

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WHERE LEADERS ARE MADE

[www.toastmasters.org](http://www.toastmasters.org)

## Toastmaster Meeting Roles

- Toastmaster
- Word of the Day
- Educational Moment
- Table Topics
- “Ah” Counter
- Timer
- Speakers
- General Evaluator
- Evaluators

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WHERE LEADERS ARE MADE

[www.toastmasters.org](http://www.toastmasters.org)

## Word of the Day

### ad·vo·cate

[advocate] 

**NOUN**

- a person who publicly supports or recommends a particular cause or policy:  
 "he was an untiring advocate of economic reform"  
*synonyms: champion · upholder · supporter · backer · promoter · proponent · [more]*

**VERB**

- publicly recommend or support:  
 "they advocated an ethical foreign policy"  
*synonyms: recommend · prescribe · commend · advise · favor · approve of · support · back · uphold · subscribe to · champion · campaign on behalf of · stand up for · speak for · argue for · plead for · press for · lobby for · urge · promote · espouse · endorse · sanction · vouch for*

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WHERE LEADERS ARE MADE

[www.toastmasters.org](http://www.toastmasters.org)

## Table Topics

- If you created your own late-night talk show, podcast, or You Tube Channel, who would you invite as your first guest to be interviewed?
- Table Topics Idea Handouts

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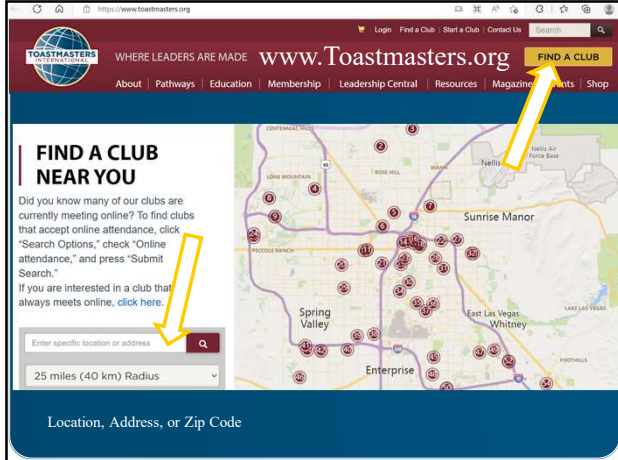
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**Establish a new Toastmasters Club!**

How about a Toastmasters Club focused on Advocacy?

How about a lunchtime Toastmasters Club at your workplace?

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**Advocacy Wins!**

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4. Tell Your Story; Present Your Ideas
5. Volunteer
6. Find and Engage the Experts
7. Enhance your communication skills

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6. Find and Engage the Experts
7. Enhance your communication skills
8. Be active in your community

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## Partners in Policymaking

August 2015  
Partners  
In  
Policymaking  
Graduation



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## Partners in Policymaking

- Designed for individuals with developmental disabilities and their families and/or caregivers.
- The goal is to develop productive partnerships between people who need services and those who are in a position to make policies and laws.
- Provides information and resources to develop skills needed to:
  - Create positive change for current issues
  - Develop innovative approaches and understand best practices,
  - Understand policymaking and legislative processes at local, state and national levels.
- Graduates of the Partners program are in a better position to help change these policies and laws through the knowledge they gain in this program.
- Graduates will have the opportunities to talk with professionals in the developmental disabilities field as well as become confident in their ability to connect with organizations and opportunities within their communities.

Partners in Policymaking — Nevada Governor's Council on developmental disabilities ([nevadadccouncil.org](http://nevadadccouncil.org))

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## Partners in Policymaking

- History and Future of Disabilities
- People First Language
- Quality and Inclusive Education
- Person Centered Planning
- Self Determination
- Informed Choice
- Housing
- Family Support and Supported Living
- Accessibility and Assistive Technology
- Supportive and Competitive Employment
- Parliamentary Procedure and Serving on Boards
- Community Organizing and Advocacy
- Government:
  - Local, State and Federal Policy
  - Legislation and Process

Partners in Policymaking — Nevada Governor's Council on developmental disabilities ([nevadadccouncil.org](http://nevadadccouncil.org))

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**Partners in Policymaking**

- 2023 Partners in Policymaking Class
- Course dates are January 2023 – August 2023
- Classes are online via zoom.
- Apply from September 2 through November 30, 2022

Partners in Policymaking – Nevada Governor's Council on developmental disabilities (nevadaddcouncil.org)

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**NEVADA GOVERNOR'S  
COUNCIL ON  
DEVELOPMENTAL  
DISABILITIES**

Experience Based Informed Choice, Inclusion and Equality

Nevada Governor's Council on developmental disabilities – Experience Based Informed Choice, Inclusion and Equality (nevadaddcouncil.org)

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Nevada Governor's Council on Developmental Disabilities

**NGCDD**



<https://www.nevadaddcouncil.org/>

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Nevada Governor’s Council on Developmental Disabilities  
(NGCDD)

Funded annually by the Federal Department of Health and Human Services with matching funds of 25% appropriated by the Nevada Legislature.

The Nevada Department of Health and Human Services is the Designated State Agency for the NGCDD

NGCDD operates in partnership with

- [Nevada Disability Advocacy and Law Center \(NDALC\)](#)
- [Nevada Center for Excellence in Disabilities \(NCED\)](#)

under the “Developmental Disabilities Network.”

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Nevada Governor’s Council on Developmental Disabilities  
Authorized in the Federal I/DD Assistance and Bill of Rights Act (DD Act)

What is the DD Act and why is it important?

Gives people with I/DD equal rights to access and be included in their communities.

- In every state and territory, programs authorized by the DD Act empower individuals with developmental disabilities and their families to help shape policies that affect them.
- DD Act programs conduct important research and test innovative new service delivery models.

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Nevada Governor’s Council on Developmental Disabilities

**Five Year State Plan**  
October 2021 through September 2026

Provide Resources, Support, Education, Training, Access

Goal 1 - Informed Decisions

Goal 2 - Participate in advocacy and policy making activities

Goal 3 - Develop and strengthen systems to improve quality in services

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Notice of Funds Available for Federal Fiscal Year 2023

October 1, 2022 through September 30, 2023

The NGCDD is seeking proposals for grants to help meet the Council's goals and objectives listed in the Draft Five-Year State Plan for Federal Fiscal Year 2022-2026 which can be found at [www.nevadaddecouncil.org](http://www.nevadaddecouncil.org).

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First Responder Education and Training Grant

Original grants were focused on training first responders to recognize and effectively interact with individuals with autism and other neurodevelopmental disabilities.

Due to the success of the trainings funded by the grants, the latest grant is to "train the trainer" such that more opportunities to educate and train first responders can be provided.

In the Nevada Legislative Sessions 2019 to 2020, a law was amended such that persons applying for a first responder license must complete training concerning identifying and interacting with persons with developmental disabilities.

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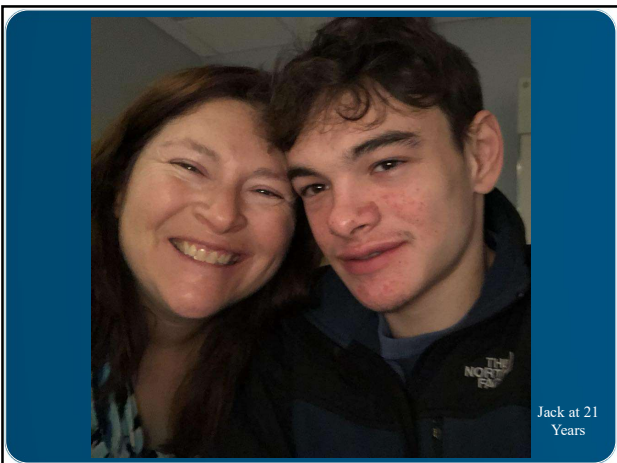
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5. Volunteer
6. Find and Engage the Experts
7. Enhance your communication skills
8. Be active in your community
9. Set Your Goals

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### Goal Setting Workshop Handouts

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Never doubt that a small group of thoughtful, committed citizens can change the world.

Indeed, it is the only thing that ever has.

Margaret Meade



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