



WELCOME!

Hello Families!

We are thrilled you are joining us for two big firsts this weekend: the first ALD Family Weekend, and the first ever Camp at Home Family Weekend at The Painted Turtle! The Painted Turtle is a place where children with serious medical conditions celebrate just being kids. Through innovative camp programs, children with more than 73 medical conditions visit The Painted Turtle each year, reclaiming the joys of childhood. A member of Paul Newman's renowned SeriousFun Camps, The Painted Turtle has served over 60,000 children and their families through its summer, family weekend, and in-hospital camp programs since opening its gates in 2004. We are delighted that you are now part of our camp family!

The Painted Turtle aims to provide programming and support to the whole family. Family Weekend sessions present the unique opportunity for families to network, share resources and stories, and make lasting connections and friendships with other families who understand their daily lives. Although this weekend is going to look a little different than what we had first imagined, we hope you find the opportunity to make connections that will last until we can be at Camp together in the future.

Thank you to Dr. Van Haren from Stanford, Nic and Alison Adler, Gina Cousineau, Janis Sherwood, and Kathleen O'Sullivan-Fortin for their vision behind this ALD Family Weekend. We are grateful for their time and hearts that have brought this weekend to life.

We encourage you to embody the theme of "Lotta Love" this weekend with your family, with The Painted Turtle, and with the ALD community. We have a lotta learning, a lotta fun, and a lotta bit of silliness planned for the weekend. Enjoy Camp at Home, and we will look forward to seeing you in Lake Hughes soon!

Camp Hugs and High Fives,

The Painted Turtle Team



ALD FAMILY WEEKEND

Dear Campers & Families -

On behalf of the Adler family and the Stanford ALD Program, welcome to the ALD Family Weekend!

We are excited to bring you a weekend full of connection, hope, action, and, of course, fun! During these two days, you'll get a chance to create connections with others in our community, participate in family fun activities, learn about current and future therapies, and consider steps you can take to make life better for your family and others with ALD.

As many of you know, camp was originally supposed to take place this year at The Painted Turtle in Lake Hughes, CA. Due to COVID-19 we could not meet in person, but the silver lining is so many families will be attending that would not have been able to make the trip. While we are thrilled to bring everyone together online, we hope you all will be able to join us in person next year.

Our sincere thanks to our planning team, our speakers, and our program sponsors. This year's sponsors include:

- The Stanford Division of Child Neurology
- ALD Connect
- Fight ALD
- Be a Hero Become a Donor

See you at camp!

Sincerely, Alison Adler, Nic Adler, & Dr. Keith Van Haren







ALD PLANNING TEAM



Dr. Van Haren - Stanford, Department of Neurology Child neurologist who oversees the ALD Clinic and Research Program at Stanford. The ALD Program cares for men and women across the age spectrum and is actively engaged in ALD clinical trials, laboratory research, and the continuous improvement of clinical care for ALD families.



Nic, Alison, Cash & Lucas Adler Lucas was diagnosed with ALD through newborn screening in California in 2017. Ever since, Nic & Alison have been working on ways to forward a cure and build a stronger ALD community. Recently, they started The Lucas Project which raised \$104,000 for ALD research at Stanford.



Gina Cousineau Mama G's Lifestyle MamaGsLifestyle.com









Janis Sherwood
Founder Fight ALD - Fighting Illness Through Education
www.fightald.org



Kathleen O'Sullivan-FortinTreasurer/Patient Advocate/Board of Directors ALD Connect, Inc.

STAY CONNECTED, FOLLOW US!



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www.aldfamilyweekend.com



THE PAINTED TURTLE TEAM





April Tani Director of Camp Programs and Initiatives



Michelle Melendez
Health Center Director



Amanda Willms
Events Manager



Teresa Molello
Hospital Outreach Manager



THE PAINTED TURTLE TEAM





Emily Rodgers Program Coordinator



Katie Griffith
Residential Life Manager



If you have Questions at any point throughout the weekend, feel free to call The Painted Turtle at: **661-886-3073**

STAR MODEL

Camp has four basic rules called The **STAR** Model that we ask all campers and families to adhere to when participating in programs with The Painted Turtle. We will follow The **STAR** Model this weekend so that everyone has the best experience possible!



STAY SAFE!

We must all stay safe and follow our house rules at all times. Being safe together will allow us all to have a good time.



TRY NEW THINGS!

To have the best experience possible at The Painted Turtle, we encourage all of the campers and families to try something new.



ALWAYS BUILD UP NOT DOWN!

Having someone else put you down never feels good, so we do not do it at The Painted Turtle. Always be encouraging and thoughtful of others' feelings and take time to build them up.



RESPECT!

Always respect yourself, others, the property of others, and the environment in which we live. Treat other people the way you would want to be treated.

HOW WILL YOUR FAMILY PRACTICE THE STAR MODEL THIS WEEKEND?



TPT CORE VALUES

The Painted Turtle shell is a symbol of our commitment to create a **community** that uplifts and empowers all who are a part of it. By leading with **heart**, we pursue our **vision** to foster a culture of **compassion**, founded on a strong sense of **trust**. With that foundation, we have the **courage** to try new things and enjoy every present moment with immense **joy**!



COMMUNITY - Work as a community to create impactful change.



HEART - Operate with intention from the heart.



VISION - Strive towards a greater vision by pursuing growth, exhibiting leadership, and embracing the power of new ideas.



COMPASSION - Serve with compassion to foster a supportive and inclusive environment.



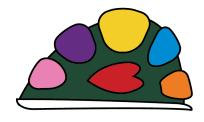
TRUST - Build trust by acting with integrity, reliability, and mutual respect.



COURAGE - Embody courage: be bold, be creative, be our best selves!



JOY - Choose Joy.



SATURDAY OVERVIEW

(All times are PST)

9:00 AM: Welcome!

9:30 AM: Family Meet & Greet

10:15 AM: Break

10:30 AM: Family Activity

11:30 AM: Lunch!

12:30 PM: Parents: Connection Session

Camper & Teen Activity

1:30 PM: Break

1:45 PM: Parents: Educational Session

Camper & Teen Activity

2:45 PM: Break

3:00 PM: Cooking Class with Gina

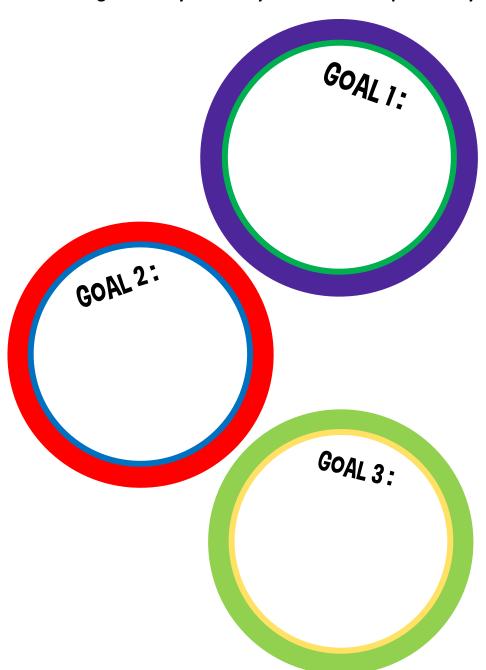
3:45PM: Break

4:00 PM: Family Campfire

4:45 PM: See You Tomorrow!

GOALS OF THE DAY

What are 3 goals that your family wants to accomplish today?



CONNECTION SESSION

Navigating Family Life with ALD

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	_
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WHAT ARE SOME TAKEAWAY PIECES, NEXT STEPS?	1
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	A: Standards of Care: Neuro, Endo, BMT	
Tarcin QQ	na Standards of Carc. Heart, Lildo, Birri	•
<i>[</i>	WHAT ARE SOME TAKEAWAY PIECES. NEXT STEPS?	



BABY SHARK SING ALONG

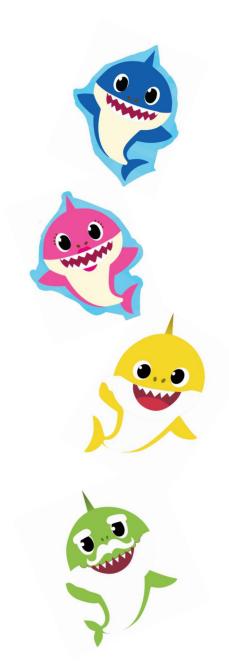
Baby shark, doo doo doo doo doo doo Baby shark, doo doo doo doo doo Baby shark, doo doo doo doo doo Baby shark!

Daddy shark, doo doo doo doo doo doo Daddy shark, doo doo doo doo doo doo doo Daddy shark, doo doo doo doo doo Daddy shark!

Let's go hunt, doo doo doo doo doo doo Let's go hunt, doo doo doo doo doo Let's go hunt, doo doo doo doo doo Let's go hunt!

Run away, doo doo doo doo doo doo Run away, doo doo doo doo doo Run away, doo doo doo doo doo Run away!

Safe at last, doo doo doo doo doo doo Safe at last, doo doo doo doo doo doo doo doo Safe at last, doo doo doo doo doo Safe at last!



HEAD & SHOULDERS SING ALONG

Head and shoulders baby 1, 2, 3

I said head and shoulders baby 1, 2, 3

Knees and ankles baby 1, 2, 3

I said knees and ankles baby 1, 2, 3

Head and shoulders, knees and ankles, baby 1, 2, 3

I said head and shoulders, knees and ankles, baby 1,2,3

Scoop the ice cream baby 1,2,3

I said scoop the ice cream baby 1,2,3

Head and shoulders, knees and ankles, scoop the ice cream baby 1, 2, 3

I said head and shoulders, knees and ankles, scoop the ice cream baby 1, 2, 3

Pick the apple baby 1,2,3

I said pick the apple baby 1,2,3

Head and shoulders, knees and ankles, scoop the ice cream, pick the apple baby 1, 2, 3

I said head and shoulders, knees and ankles, scoop the ice cream, pick the apple baby 1, 2, 3

Around the world baby 1,2,3

I said around the world baby 1,2,3

Head and shoulders, knees and ankles, scoop the ice cream, pick the apple, around the world baby 1, 2, 3

I said head and shoulders, knees and ankles, scoop the ice cream, pick the apple, around the world baby 1, 2, 3



WE COME FROM THE MOUNTAINS

We come from the mountains
Living in the mountains
Go back to the mountains and turn the world around *<clap clap>*We come from the mountains
Go back to the mountains and turn the world around

We come from the water
Living in the water
Go back to the water and turn the world around *<clap clap>*We come from the water
Go back to the water and turn the world around

We come from the fire
Living in the fire
Go back to the fire and turn the world around *<clap clap>*We come from the fire
Go back to the fire and turn the world around

We come from the sky
Living in the sky
Go back to the sky and turn the world around *<clap clap>*We come from the sky
Go back to the sky and turn the world around

We come from the turtle
Living in the turtle
Go out from the turtle and turn the world around *<clap clap>*We come from the turtle
Go out from the turtle and turn the world around

We come from the mountains
Living in the water
Go out from the fire and turn the world around *<clap clap>*We come from the sky
Go out from the turtle and turn the world around









STARS IN THE SKY

Stars in the sky, stars in the sky
Bring the summer right back to me
Tell me you'll try, tell me you'll try
To think about me whenever you see those Stars in the sky



It's just a letter from a friend of mine
A little picture from another time
A little picture of a place that we used to go
A word or two about a friend we miss
A fond reminder of a promised kiss
A fond reminder of a vow we made long ago



Stars in the sky, stars in the sky
Bring the summer right back to me
Tell me you'll try, tell me you'll try
To think about me whenever you see those Stars in the sky



We went away when we were very young
To find the person that we would become
To find the person that was hidden somewhere inside
What we discovered there it still holds true
The friends you make become a part of you
The friends you made will each return to you like the tide



Stars in the sky, stars in the sky
Bring the summer right back to me
Tell me you'll try, tell me you'll try
To think about me whenever you see those Stars in the sky



And if by chance you should be going there
Please take this message that I hope you'll share
Please take this message to the ones too young to have learned
The time is short and there's so much to do
Don't waste a moment of what's given to you
Don't waste a moment 'cause you'll never see it returned



Stars in the sky, stars in the sky Bring the summer right back to me Tell me you'll try, tell me you'll try





To think about me whenever you see those Stars in the sky, Stars in the sky

SUNDAY OVERVIEW

(All times are PST)

8:00 AM: Yoga (optional)

9:00 AM: Welcome!

9:30 AM: Parents: Educational Session

Camper & Teen Activity

10:30 AM: Break

10:45 AM: Parents: Connection Session

Camper & Teen Activity

11:45 AM: Lunch!

12:45 PM: Parents: Connection Session

Camper & Teen Activity

1:45 PM: Break

2:00 PM: Family Fun with PUN!

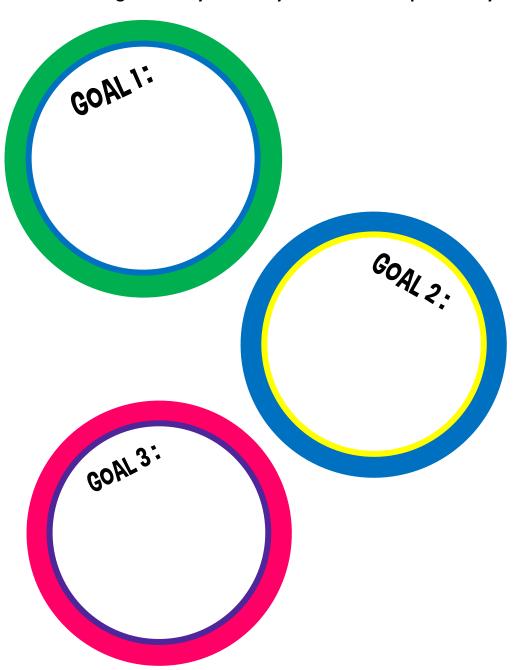
3:00 PM: Camp Closing

3:30 PM: See You Next Time!



GOALS OF THE DAY

What are 3 goals that your family wants to accomplish today?





Future Therapies: Gene Therapy for ALD, Gene Therapy for AMN. Small Molecular Therapy

AMN, Small Molecular Therapy
WHAT ARE SOME TAKEAWAY PIECES, NEXT STEPS?

CONNECTION SESSION

Converting Anxiety into Action: Fundraising, Volunteering, Organizing, Peer Counseling

WHAT ARE SOME TAKEAWAY PIECES, NEXT STEPS?
A control tube of



Inspiration!

WHAT ARE SOME TAKEAWAY PIECES, NEXT STEPS?



QUESTIONS FOR Q&A



Find and circle all the words in the list below!

B	D	G	U	X	S	W	I	M	N
A	N	P	F	A	H	R	L	F	I
C	E	W	T	E	N	T	S	I	T
K	F	S	M	0	R	E	S	R	R
P	0	R	Y	I	N	G	Z	E	E
A	0	C	A	M	P	S	I	T	E
C	D	K	H	S	A	K	A	L	S
K	W	D	Z	Q	H	I	K	E	M

TENTS
FIRE
HIKE
SWIM
SMORES



TREES
BACKPACK
CAMPSITE
FOOD
SKI

What do you call a dinosaur that is sleeping? A dino-snore!

What is fast, loud, and crunchy? A rocket chip!

Why did the teddy bear say no to dessert? Because she was stuffed.

What has ears but cannot hear? A cornfield.

What did the left eye say to the right eye? Between us, something smells!

What do you get when you cross a vampire and a snowman? Frost bite!

What did one plate say to the other plate? Dinner is on me!

Why did the student eat his homework? Because the teacher told him it was a piece of cake!

When you look for something, why is it always in the last place you look? Because when you find it, you stop looking.

What is brown, hairy, and wears sunglasses? A coconut on vacation.

What do you call a fake noodle? An impasta!

What did the Dalmatian say after lunch? That hit the spot!

Why did the kid cross the playground? To get to the other slide.

How does a vampire start a letter? Tomb it may concern...

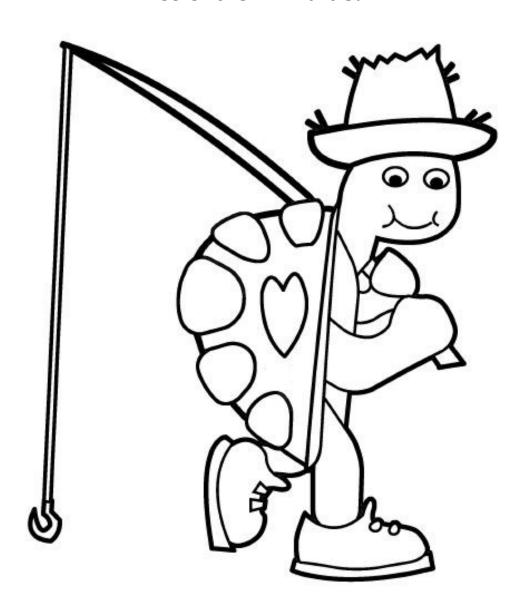
How do you make a lemon drop? Just let it fall.

What kind of tree fits in your hand? A palm tree!

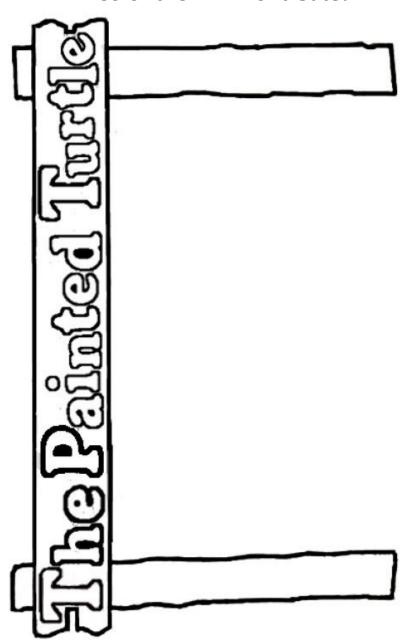
What kind of water cannot freeze? Hot water.



Color the TPT Turtle!



Color the TPT Front Gate!

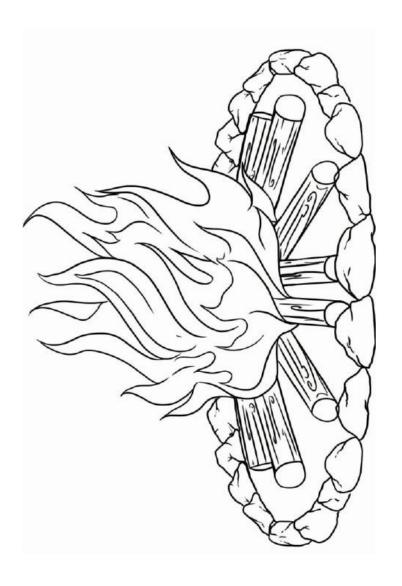


Color TPT's Finest Friends- Stevie and Carlitos!

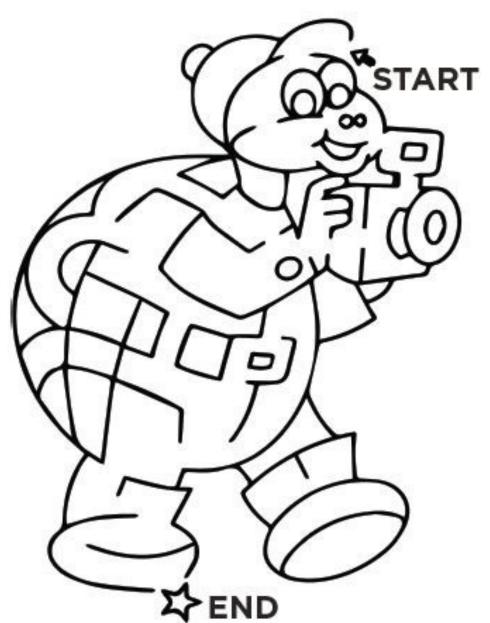


besties.

Color the Campfire!



Complete the Turtle Maze!



Unscramble the words!







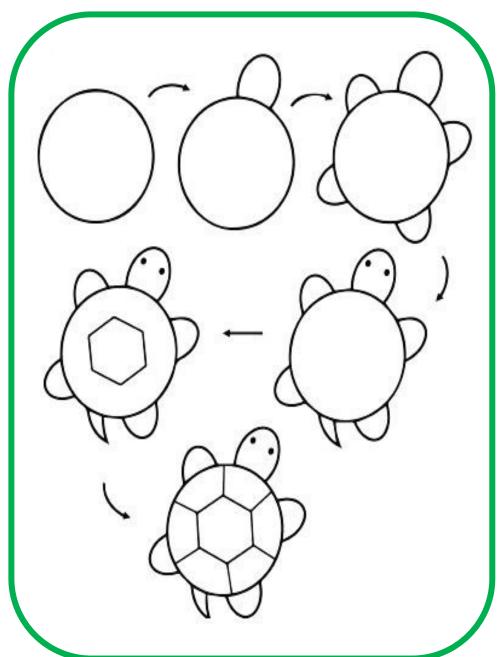






NGWSIMIM

Learn how to draw a turtle!



Practice drawing your own turtle!

MAGIC MOMENTS FROM ALD FAMILY WEEKEND!

