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NATIONAL CONVENTION

June 21 – 24, 2023 • Orlando, FL

Our Family

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Financial Advisor – Northwestern Mutual



- Lucca is 8 years old, diagnosed shortly after birth with PWS.
- Enjoys horse-back riding, swimming, coloring and playing outside with friends.
- Alex is 13, attending 7th grade, loves to play Soccer. Wife Kenna is V.P. of Operations at our household and Occupational Therapist at a local hospital.
- Ivailo holds an MBA in Finance, Chartered Special Needs Consultant through American College. Enjoy traveling and tries to make it to as many kids activities as possible.



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Creating Financial Security for a Loved One with Special Needs

- 82% of caregivers are concerned they do not have enough financial resources to last their disabled relative's lifetime.
- 77% of caregivers are concerned they won't be able to retire.
- 70% believe they will have to compromise their own retirement plans in order to provide for their dependent with special needs
- 60% of caregivers with life insurance have less than \$300,000 of coverage and fewer than half have the protection of whole life coverage. However, the lifetime cost of caring for a dependent with autism is between \$1.4 and \$2.4 million.
- 73% of caregivers don't have long term care insurance.
- 87% are concerned about what will happen to their child with disabilities when they (mom/dad) are no longer living.
- 59% have not written a Will addressing the special needs of their relative.
- 67% of parents have not set up a Special Needs Trust
- Only 23% of families have a formal financial plan for their dependent and only 37% work with a financial advisor.



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Keep in Mind

- It's never too soon to start planning.
- You don't have to do everything at once.
- You're not alone.



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Today's Agenda

1. Building your team
2. Developing your special needs plan
3. Special Needs Trusts
4. ABLE Plans



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Building Your Team

- Financial Professional
- Government Benefits Specialist
- Attorney (experienced in special needs)



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Developing Your Special Needs Plan

Understand where you are and where you want to go

- **You:**
 - What are your savings and spending habits?
 - What are your short-, medium- and long-term financial goals?
 - What do you want for your future?
- **Your Loved Ones:**
 - What do you envision for your loved one's life?
 - Where will they live? Who will provide day-to-day care?
 - What social activities do you want them to be a part of?



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Developing Your Special Needs Plan

Understand what benefits your loved one is eligible for:

- Social Security: Supplemental Security Income and Retirement Income
- Medicaid: Health care and custodial home care
- Vocational services
- Public school services
- Veterans' benefits

Your government benefits specialist can make sure you're not leaving money on the table.



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Supplemental Security Income

SSI/SSDI

Child under age 18 with working parents

- Parents' income, assets and household size determine child's eligibility and benefit amount

Child age 18 or older with working parents

- Adult child with special needs income and assets under \$2,000

Retired parent taking Social Security and child considered disabled before age 22

- Parents work history and credits determines additional amount of benefit

In 2023, the benefit amount could be up to \$914 a month.



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Third-Party Special Needs Trusts

- These trusts help pay for supplemental needs that can enrich the life of your loved one.
- Anyone except your loved one with special needs can contribute.
- Government benefits generally should not be affected.



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Third-Party Special Needs Trusts

1. Hire an estate planning or elder law attorney to draft your trust.
2. Consider having a bank serve as trustee.
3. Life insurance can fund a special needs trust.
4. A trust can be set up so the remaining assets pass to family members if the primary beneficiary passes away.



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ABLE or 529A Plans

Public benefits often have asset limits of \$2,000.

• ABLE (ACHIEVING A BETTER LIFE EXPERIENCE) PLANS:

- May be created any time if disability onset prior to age 26
- Nothing inside the account is deemed a resource for Medicaid determination or spend down
- The first \$100,000 inside the account does not impact Supplemental Security Income (SSI)
- 2023 – annual contribution up to \$17,000 gifting limits
- Contributions are post-tax and are not tax deductible at the federal level (some states allow deductions)
- Assets grow tax free and qualified distributions are tax free



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ABLE or 529A Plans

Used for:

- Education
- Housing
- Transportation
- Employment training
- Assistive technology
- Personal support
- Health care expenses
- Expenses that improve health, independence or quality of life



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Planning for Your Financial Future

Planning for your loved one with special needs is critical ... but it's only part of your financial plan.

What do you want for your own future?

- **Find a financial professional to help you:**
 - Identify your goals.
 - Set priorities.
 - Create and execute a customized plan.
 - Keep your plan aligned with your changing life.



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RECAP

- **ASSEMBLE YOUR TEAM:**
financial professional, government benefit specialist and attorney
- **DEVELOP A SPECIAL NEEDS PLAN**
- Understand your current situation.
- Decide what you want for the future.
- Get the benefits your loved one is eligible for.
- Estimate future cost of care.
- Establish and fund a special needs trust and/or ABLE plan.
- **DON'T FORGET TO PLAN FOR YOURSELF**



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 Prader-Willi Syndrome Association | USA

THANK YOU



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(941) 312-0400



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Legal Solutions for Families and Children with Prader-Willi Syndrome

Lisa B. Thornton, Attorney

President--Utah Prader-Willi Syndrome Association (17 years); PWSA (USA) Past Board Member (6 years); Board Member of The Curtis Center and University of Utah LEADD Program (college-like programs for adults with disabilities)

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Lisa Thornton Family



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My Daughter Kate!



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Kate is 19!



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Missionaries from the Church of Jesus Christ of Latter-day Saints have volunteered every conference since 2011, donating thousands hours to make this all possible for your children!



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Set “Impossible” Goals at the PWSA | USA National Convention!



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Utah Security Project

- Utah got a \$64,000 grant to purchase and install security products for PWS families
- Security failures cause huge anxiety to families
- Families start too late to create secure systems and no Utah family had adequate security despite numerous conferences and articles!
- Emerging best practices:
 - New self-locking fridge and pantries
 - Locking bedroom doors of siblings and parents
 - Getting (adult) strollers, cameras, and personal tracking devices allow more freedom for activity



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Let Me live one moment longer than my Kate



Lisa and Kate

Lisa understands the joy and challenges of life with a special needs child. Her daughter Kate was born with Prader-Willi Syndrome.



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Necessary legal documents

- Special Needs Trust
- Letters of Guardianship
- Durable Power of Attorney
- Advance Health Care Directive
- Will
- Revocable Trust
- Life Care Plan/Letter of Intent



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Legally Protect Your Child



A **Special Needs Trust (called a Third Party Supplemental Needs Trust)** will protect your child's potential benefits by keeping them under the \$2,000 limit and allowing them the extra money needed every month to make life wonderful!



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Don't make the mistake of leaving money for your child with disabilities with their sibling.



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A Special Needs Trust



- A Third Party Supplemental Needs Trust should be a stand alone document but can be included inside your will or your revocable trust.



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Who Should be the Trustee of the Special Needs trust?

- Sibling of child with disabilities?
- The guardian?
- Corporate Trustee?



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When to Fund a Special Needs Trust

Fund upon your death if:

- You don't have the money to fund the trust before your death
- You don't want to have to file a separate tax return for the trust which will create additional expense and work



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When to Fund a Special Needs Trust

Fund upon your death if:

- You have plenty of money to meet your needs
- You want to know a specific amount of money is available for your child
- You have a large estate and are using strategies to reduce your estate tax liability by making gifts to the special needs trust
- Grandparents donate to grandchild with PWS
- Relative wants to reduce their taxable estate by making gifts to Special Needs Trust
- Money or assets in the trust may provide some protection from creditors
- Information on filing taxes for trust: <https://www.specialneedsalliance.org/the-voice/filing-a-tax-return-for-a-special-needs-trust-what-a-trustee-needs-to-know-at-tax-time/>



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How to Fund a Special Needs Trust—A bucket that must be filled

During your life:

- Savings
- Investments in stock
- Investments in mutual funds
- Donations from relatives

At death:

- Retirement plans
- Your home
- Savings and Investments
- Life Insurance
 - Second to die policies
 - Whole life policies
 - Term policies



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How Much Money Will you Need to adequately fund the Special Needs Trust?

Use a Calculator to estimate

Online calculators or making estimates of your expenses will give you a good idea of how much your child will need every month to have a great life!

Don't rely exclusively on government benefits that may not be around forever



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You are Planning for Two Generations

Below is an example of a time line:

	2019	2021	2025	2029	2042	2053	Future
Sid	57	59	63	67 (retires)	80 (dies)		
Lisa	56	58	62	66	79	90 (dies)	
Ellyn	26	28	32	36	49	60	
Emma	20	22	26	30	43	54	
Jane	18	20	24	28	41	52	
Kate	16	18	22	26	39	50	Kate dies
		(SSI/ Guardians)	(Out of school. Group Home?) Apply for SSDI & Medicare.)	(Sid's medical insurance stops. Estate distribution)		(Special needs trust funds. to siblings)	(Distribute SNT Assets)



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Email Lisa Thornton
to get a sample
template of a special
needs trust and life
care plan.

Lisa@lisathorntonlaw.com

Google Special Needs
Alliance to find attorney
in your state



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ABLE ACCOUNT: A Better Life Experience

<http://www.ablenrc.org/> (good site for details)

Positives:

- The ABLE account allows your child to earn money and deposit up to \$17,000 per year
- Income earned by the account is not taxed
- If the ABLE account stays \$100,000 or less, the child with disabilities will still remain eligible for full SSI benefits
- ABLE account funds can be used for housing, transportation, education, doctor visits, legal fees, burial costs, assistive technology, etc.



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ABLE ACCOUNT: A Better Life Experience

Negatives:

- After your child passes away, the state can claim funds left in the ABLE account to pay for past Medicaid expenditures
- If Parents put their own money into an ABLE account, it may be lost
- Thus, Special Needs Trusts are still needed for your child with PWS



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What is Guardianship

- Guardianship is a legal proceeding where parents petition the court to determine the adult child is unable to manage their decisions because of incapacity. The court issues a document called “Letters of Guardianship” that allows parents (and maybe others such as older siblings) the legal authority to continue in their decision making role as parent.



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Why parents need Guardianship

- When your child with PWS turns 18, the law considers them an adult and they are presumed competent to make all decisions relating to their life including finances, medical care, and where to live.
- Individuals with PWS are vulnerable and at greater risk for harm without guardianship.
- Without guardianship, police will often wait 72 hours to look if adult with PWS wanders off or runs away.
- Without guardianship, insurance companies, physicians will not speak with parent regarding health issues. (Online health portals shut down to parents)



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Seek full or plenary Guardianship

- Our children need full guardianship
- Partial guardianship, though preferred by courts, is not usually appropriate for our children.
- I have never had any trouble getting full guardianship for an adult with Prader-Willi syndrome in court.



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Change the laws in your state: It is an easy process!

- **Guardianship is a great area for legislative reform in your state:**
 - reduced court filing fees (\$35 v. \$360)
 - placed forms on court website
 - required no attorney for adult child if they have less than \$20,000
 - no annual reporting requirement for parents



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Substitutions for Guardianship: Not recommended

- If you do not seek guardianship, consider durable power of attorney, health care directives and estate planning for those with PWS



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Supplemental Security Income



- SSI should be applied for when the child turns 18
- Maximum benefit is currently approximately \$914 a month. Make sure you turned in a rental form!
- Denial is not uncommon on first try, but success on appeal for adults with PWS is very high and back payments often awarded. See PWSA | USA website for forms.



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Medicaid



- Provides long-term medical care for children with disabilities
- Children who receive SSI automatically qualify for medical insurance, but must apply for Medicaid



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Protection for Parents



Power of attorney, medical directive, will, life care plan, letter of intent, and revocable trust.



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Durable Power of Attorney



Names those to act for you in financial matters if you become disabled or incapacitated



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Medical Directive



Names the people you want acting on your behalf when you are unable to communicate your desires for medical treatment

Google “advance health care directive” and your state’s name and you will be able to find the form to complete



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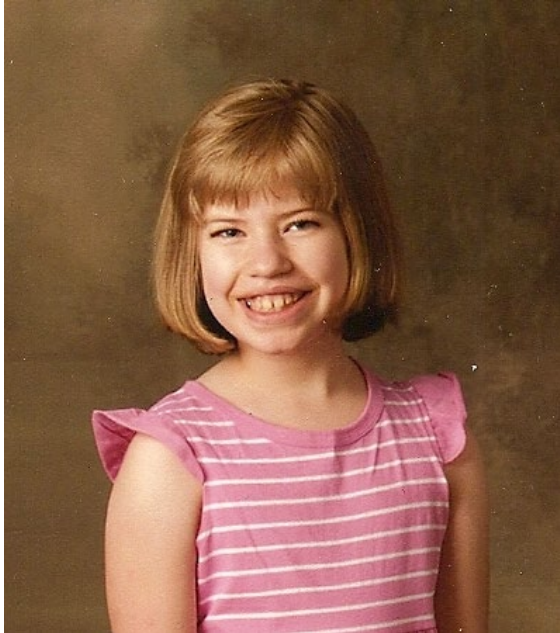
Will

- Allows you to direct the distribution of property and leave assets to your children, grandchildren, charities, or other heirs
- Allows you to nominate a guardian for your minor children or child with PWS but this is not the required formal legal guardianship addressed above.
- If you die without a will, state law determines how to distribute your assets and a child with disabilities may receive assets of more than \$2,000, thereby becoming ineligible for SSI, Medicaid, your state waiver programs, etc.
- Make sure you include language in your will and/or revocable trust that says any distribution to your child with disabilities shall be distributed for their benefit to trustee of the [child's full name] Third Party Discretionary Supplemental Needs Trust.



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Revocable Trust



- The revocable trust allows your family to avoid probate and the accompanying delay, court costs, publicity, and attorney fees
- The revocable trust allows assets to pass automatically to your heirs without delay and excessive costs.



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Letter of Intent



While not a legal document, this provides future caregivers and guardians with a clear understanding the parents' visions and hopes for their child's future



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Life Care Plan



- Outlines the child's particular needs and preferences
- This type of planning should address questions as to where the child will live, who will have a personal interest in the child, and how all of the child's financial, personal, physical, emotional and spiritual needs will be met.



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Keep your documents updated



Laws and circumstances change. Your legal documents should be revisited with each life change.



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