

Legal Solutions for Families with Children with Prader-Willi Syndrome

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My Daughter
Kate, who is
10!



We are all afraid up here, but we can all help!



REACH OUT, HELP THOSE IN YOUR STATE: MAKE YOUR STATE STRONG!

- Gather families in your state
- Hold fundraising and awareness events
- Create a Community of Caring for your child



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.

Necessary legal documents

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

Email Lisa Thornton for copies of
Special Needs Trust and Letter of
Intent: lisa@lisathorntonlaw.com



Legally Protect Your Child

A **special needs trust** will protect your child's potential benefits and allow her the extra money she will need every month to make her life wonderful!



Don't make the mistake of leaving money for your child with PWS with his sibling.



A Special Needs Trust

- Allows parents to leave money for a child with PWS without disqualifying them from government benefits
- Provides extra money for child
 - every month to enrich his life.
 - \$701 a month is the current
 - benefit under SSI.



Who Should be the Trustee of the Special Needs trust?

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

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.
- If you don't want to have to file a separate tax return for the trust (depending upon the amount of interest made by the money invested in the trust), which will create additional expense and work.

Fund during your lifetime if...

- You have plenty of money to meet your needs and putting money into the trust will not jeopardize your personal financial security
- You wish to have the security of knowing there is a specific amount of money available for your child with PWS.
- You have a large estate and are using strategies to reduce your estate tax liability by making gifts to the special needs trust.
- Grandparents may want to convey some amount of money—either during life or at death—to assist a grandchild with special needs.
- Grandparents or other relatives or friends may want to reduce their taxable estate by making gifts of money to your child with PWS. These gifts should be made to the Special Needs Trust rather than the child in order to protect eligibility for government benefits.
- Money or assets in the trust may provide some protection from creditors.

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:

- 401k, other assets
- Life Insurance
 - Second to die policies
 - Whole life policies
 - Term policies

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

Use a Calculator to estimate

- Met Life:
<http://www.metlifeiseasier.com/specialneedscalculator/index.asp>
- Merrill Lynch:
<http://www.wealthmanagement.ml.com/wm/pages/Special-Needs-Financial-Services.aspx>

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

You are Planning for Two Generations

Below is an example of a time line:

	2009	2021	2025	2029	2042	2053	
Sid	47	59	63	67 (retires)	80 (dies)		
Lisa	46	58	62	66	79	90 (dies)	
Ellyn	16	28	32	36	49	60	
Oliver	11	23	27	31	44	55	
Emma	10	22	26	30	43	54	
Jane	8	20	24	28	41	5	
Kate (PWS)	6	18	22	26	39	50	
		(SSI/ Guardianship)	(Out of school. Group Home ?)	(Sid's medical insurance stops. Apply for SSDI & Medicare.)		(Special needs trust funds. Estate distribution.)	Kate dies Distribute to siblings.

Legally protect your child by securing guardianship

- An 18 year-old adult with PWS is considered an adult and presumed competent unless a court determines otherwise
- Without guardianship, parents may not be able to help with medical or financial decisions for their child
- Secure guardianship as close to the child's 18th birthday as possible

SOCIAL SECURITY INCOME

- SSI should be applied for when the child turns 18
- Current maximum benefit is \$701 a month
- Denial is common on first try, but success on appeal for adults with PWS is very high and back payments often awarded
- www.pwsausa.org/support/crisisteam/SSI.htm for forms to apply



Medicaid

- Provides long-term medical care for children with PWS
- Children who receive SSI automatically receive insurance through Medicaid



Protection for Parents

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



Power of Attorney

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





Medical Directive

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

Google “advanced health care directive” and the name of your state to find your state form.

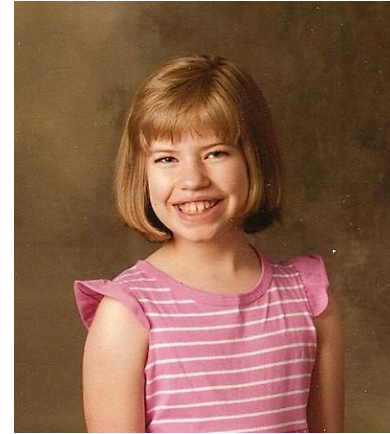
For California:

<http://ag.ca.gov/consumers/pdf/AHCDS1.pdf>

Will

- Allows you to direct the distribution of property and leave assets to your children, grandchildren, charities, or other heirs
- Allows you to name a guardian for your minor children
- 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 and become ineligible for SSI, Medicaid, and the Katie Becket Waiver.
- Make sure you include language in your will and/or revocable trust that says any distribution to your child with PWS shall be distributed for her benefit to trustee of the Kate Thornton Third Party Discretionary Special Needs Trust.

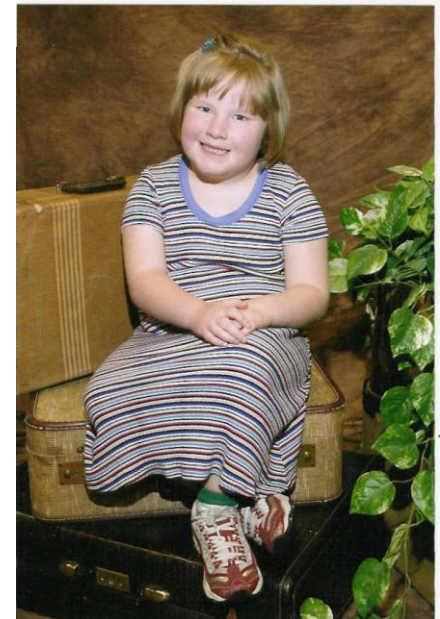
Revocable Trust



- 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.

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





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, emotional and spiritual needs will be met

Keep your documents updated

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

