

# Legacy of HOPE

Estate planning tips for friends of the PKD Foundation



## “We Want a Cure”

*Toni and Dennis Stuart’s Legacy of Hope*

For Toni Stuart of Las Vegas, learning that she has autosomal dominant polycystic kidney disease (ADPKD) 10 years ago came as a complete shock. Her parents did not have the disease, and there was no known history of PKD in her family.

Approximately 10 percent of people diagnosed with ADPKD have no family history of the disease. It develops as a spontaneous (new) mutation. Toni had a steep learning curve, and she channeled all of her efforts into investigating the disease and her options. She quickly learned that even through a spontaneous mutation, she still had a 50 percent chance of passing PKD on to each of her two sons.

It also distressed her to learn about the autosomal recessive form of the disease (ARPKD) that affects babies and children. “I could hardly stand it,” she said.

Determined to continue doing everything possible to support the PKD Foundation in its mission to end all forms of PKD, Toni took over leadership of the Walk in Las Vegas in 2017, where she and Dennis planned to relocate.

At the time, the Stuarts lived in Kingman, Arizona. It was two-and-a-half hours each way between Kingman and Las Vegas. Toni is grateful that many of their Walk team members at last year’s Las Vegas Walk were friends from Kingman. “It’s nice to have that support. Where we live now, we have a big recreation center, and there are different groups,” she says. “I’m getting more involved in these other activities so I can meet more people and get more connections. I’m really motivated to grow this Walk.”

The Las Vegas Walk for PKD on May 4<sup>th</sup> will be Toni’s third Walk, and Dennis will be with her every step of the way.

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**Toni and Dennis Stuart (top)  
and during the Walk (bottom)**



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# The Living Trust: Partner to a Will

The **revocable living trust** has become a common means of transferring property between generations.

The concept is quite simple. When you establish a trust, you create an artificial “owner” for the property placed in the trust. The trust becomes the owner of property to be managed for your own benefit or the benefit of your loved ones.

With the trust in place, your assets and/or income are managed by a trustee according to the terms you set. You can be the trustee yourself or appoint another to serve in that capacity.

You can change or revoke your living trust at any time. That is why it is referred to as a revocable living trust. Unlike a will, trusts are not generally filed as public documents so more privacy can be maintained if desired.

## A will as backup

Having a will in place is probably a wise choice even if you decide to make use of a revocable living trust, joint ownership or other arrangements to handle the majority of your estate distribution.

Frequently, a “pour-over” will is used in conjunction with a living trust and/or other ways of transferring assets. For example, it may not be convenient to place household items and valuables such as collections, jewelry and family heirlooms in a living trust. In the absence of a

will, they will be disposed of according to state laws, as if you had no other plan.

A will can direct that any property not transferred in your trust “pour over” into the trust at the end of your lifetime and be distributed according to the trust provisions.

## Charitable dimension

Remember that, like a will, living trusts function according to your instructions. If, for example, you would like to make charitable gifts using assets in a living trust, you must specify in the trust the assets are to go to one or more charitable organizations. If you would like for your trustee to be able to make charitable gifts on your behalf this should be stated in the trust document as well.

If you have a living trust as part of your estate plans, you may wish to consider using it in conjunction with your will and other plans to make charitable gifts. Your attorney can advise you, and we will be happy to discuss charitable giving strategies with you and your advisors. Return the enclosed card of contact Robin Strachan, director of planned giving, at 816-268-8486 or [robins@pkdcure.org](mailto:robins@pkdcure.org).



# “We Want a Cure”

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“Toni is an absolute workaholic for PKD and preparing for the Walk,” Dennis says. “She’s right on top of everything.” He pauses and then adds, “She’s in constant pain, but I don’t think anybody knows it but me. She won’t bring anyone else down because of how she feels.”

Toni was glad when the first treatment for ADPKD called tolvaptan was approved by the Food and Drug Administration in April 2018. Yet, her ultimate goal remains the same. “I understand that there are different forms of the disease, so one treatment won’t be enough,” Toni says. “One treatment won’t work for everyone, and it isn’t a cure. We want a cure.”

The Stuarts feel lucky that their sons Sean and Bret, now in their early 30s, have had recent ultrasounds with no sign of cysts. Yet, even as they experience relief that their sons appear to be free of the possibility of PKD, the couple has decided to include the PKD Foundation in their will for a percentage of their estate.

“The Foundation means hope to me,” Toni says. “They are the ones providing funds to pay for research that will get us to a cure.”

When asked if the couple shared their decision with their sons, Toni said, “We’ve told them we have a certain amount going to the PKD Foundation. They think it’s great.”

She believes with all her heart that others who are able to include the PKD Foundation in their estate plan, as she and Dennis have done, will find joy and satisfaction in being part of this great hope: a future free from PKD.

“The money is definitely going to a good cause. It’s so important for these doctors and scientists to learn more about this disease and to better understand what causes our cysts,” Toni says. “Knowledge is everything. That’s how we get to a cure.”

## Look Beneath the Surface of Your Plans

Plans you’ve had in place for years may offer flexible ways to give. Here are some ideas:

**Life insurance as a gift:** If you own more life insurance than your family now needs, you may wish to name the PKD Foundation to receive all or a portion of the proceeds after your lifetime.

If your insurance is in the form of an annuity, you can arrange for the life insurance company to pay income to you for life, while naming the PKD Foundation as the beneficiary to receive any amount that may be left.

It’s generally a simple process. Contact your life insurance company and ask about the necessary forms.

**Retirement plans as a gift:** If you have a 401(k), IRA or other retirement plan account, you have taken a major step toward secure retirement years.

Did you know you can name a charitable organization to receive part or all of what remains in retirement accounts after you and other beneficiaries no longer need the funds? You can arrange a gift to the PKD Foundation through an IRA, 401(k) or other such retirement plan by completing an approved beneficiary designation form. Your plan administrator can provide you with the specific details of adding a charitable recipient.

**Savings and investment account gifts:** You can leave such accounts directly to the Foundation under the laws of most states through what is known as either a “transfer on death” or a “payable on death” (TOD/POD) provision. It’s easy to do—just ask your financial services provider for the appropriate forms.

**Special IRA gift:** If you are age 70½ or older and would like to make a current gift, you can give directly from a traditional or Roth IRA completely free of federal income tax (up to \$100,000 per person per year). Giving directly to the PKD Foundation from your IRA won’t increase your adjusted gross income and possibly subject your Social Security income to a higher level of taxation. Additionally, your charitable IRA gift may count towards your Required Minimum Distribution.

# Time for a Change?

Most people find they need to make modifications in their estate plans from time to time. Take this quiz to see how your existing plans compare to your current needs.

1. I have a will or other legal arrangements for distributing my property.  True  False
2. I have not retired from full-time employment since last reviewing my affairs.  True  False
3. My marital status has not changed since my last review.  True  False
4. No significant increases or decreases in wealth have occurred since my last review.  True  False
5. Children or grandchildren have not been born since my plans were last reviewed.  True  False
6. I live in the same state as when I last updated my plans.  True  False
7. I have not given away or sold assets that are left to heirs in my previous plans.  True  False
8. Charitable organizations are remembered as I wish in my plans.  True  False

This quiz is easy to score. If you answered **False** to any question, you may want to meet with your professional advisor to update your estate plans.

We will be happy to answer any questions you may have about the benefits of including charitable gifts to the PKD Foundation as part of your plans.

## Sample Bequest Language

“I [name], of [city, state, ZIP], give, devise and bequeath to the PKD Foundation, 1001 E. 101st Terrace, Suite 220, Kansas City, MO 64131, Federal Tax Identification Number #43-1266906, [written amount or percentage of the estate or description of property] for its unrestricted use and purpose. I instruct that all of my charitable gifts shall be made, to the extent possible, from property that constitutes ‘income in respect to a decedent’ as that term is defined in the Internal Revenue Code.”



## More information



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