

ADDING CHARITY TO YOUR WILL OR IRA



*A Guide to Making Your Philanthropic Wishes Come True
and Creating Your Legacy*



**National Spasmodic
Dysphonia Association**

*Adding a gift for charity to your will
or retirement plan is a simple act
with impressive results.*

What will your legacy be?

You have people that you care about, a vision that you want to fulfill, a legacy that you want to leave behind, and organizations that you truly believe in. Taking steps now to decide how your hard-earned assets are distributed when you're not here to guide them, means that what's important to you is truly honored.

Since its inception in 1989, the NSDA has become a robust association made up of individuals living with spasmodic dysphonia and related voice disorders, healthcare professionals, as well as family members and friends of those living with the disorder. Built by a community of caring people, the organization has become a place where those who are newly diagnosed can get answers, those living with a voice condition can find camaraderie, and those treating the disorder can find the latest information on research and treatment options.

Your bequest is an investment in the National Spasmodic Dysphonia Association. It is a simple way to ensure that important work can continue for years to come.

Your generosity continues to

- Fund research on spasmodic dysphonia, with the hope that one day, it can be cured.
- Provide additional support services to those with SD and related vocal conditions.
- Increase awareness of the challenges for those living with vocal disorders.
- Support our expanding Mission to create resources for related vocal disorders.
- Increase awareness of medical professionals to insure speedy diagnosis and treatment.
- Advocate for those who do not have a voice.
- Provide tools for healthcare professionals, HR professionals and others who come in contact with someone with a vocal disorder.

The next time you review your estate plan we would like to ask you to consider the NSDA!

Various ways you can leave a bequest to the National Spasmodic Dysphonia Association

There are three primary ways to leave a bequest to the NSDA.

1. Include a bequest to the National Spasmodic Dysphonia Association in your will or revocable trust.
2. Designate the National Spasmodic Dysphonia Association as a full, partial or contingent beneficiary of your retirement account (IRA, 401(k), 403(b) or pension).
3. Name the National Spasmodic Dysphonia Association as a beneficiary of your life insurance policy.

PLEASE NOTE: It's important that you to contact your tax advisor to go through all your options to maximize what you leave while minimizing the tax implications, then contact your attorney to formalize your estate plan.



According to AARP, 2 out of 5 Americans over the age of 45 do not have a will.

Gifts through Wills and Bequests

A bequest is one of the easiest gifts to make. With the help of an advisor, you can include language in your will or trust specifying a gift be made to the National Spasmodic Dysphonia Association as part of your estate plan.

Bequest Options

1. You can gift a specific dollar amount or asset.
2. You can gift a percentage of your estate.
3. You can gift from the balance of your estate.
4. You can make a beneficiary designation of certain assets.
5. You can use a donor-advised fund.

You can choose to designate that a bequest be used for a specific purpose or for general use based on the Association's needs. This provides the peace of mind knowing that your gift will be used in the most effective ways to help those with vocal disorders.

Benefits of Making a Bequest

- You leave a lasting legacy that will be remembered.
- You control the outcome of where your assets are utilized.
- It helps to secure the future of those things that are important to you.
- You know that your bequest will support your community and favorite charities in the way you intended.
- You lessen the burden of taxes on your family.
- You may enable estate tax savings.



Determined to Make a Difference

Pat Hill serves as the Area Contact Persons Coordinator for the NSDA and has also included the NSDA in her will.

"Over the years, SD has ironically made me more verbal than I've ever been. Out of voicelessness, came a voice that is loud and clear. SD has made me take stock of what is important in life and to fight for what is valuable, which is the right of everyone to be happy and productive without prejudice. SD has made me look at the wonderful things in my life and has also let me express myself in other ways. One of the best ways that I do that is by working through the NSDA."

No Will, No Control

You have worked hard and saved vigorously to accumulate assets over the course of your lifetime. What happens if there is no will?

Someone who passes without a will is subject to the following:

- Without a will, what happens to everything a person has earned will be distributed in accordance with that state's laws.
- Without a will, an administrator will be appointed by the state to determine the how everything will be dispersed.
- Without a will, the things that were important to you during your lifetime can be lost or forgotten in the process.
- Without a will your estate is likely to have an increase in the taxes required to be paid.

A will is a living document and should be reviewed regularly, as your life circumstances change.

Emma' Story

It was 1984 when I was first diagnosed with spasmodic dysphonia (SD) and had no treatment options except speech therapy. I was a single mom working as a bank teller in a busy bank in upstate New York and I still remember how badly this impacted my self-esteem. I could not even call people to my window and had to depend on the other tellers to answer my customer's questions.

The following year I moved to Florida and thought I would never find another job, but I did, at a small Florida bank in the customer service department. I was never afraid of talking but so embarrassed by my voice and tired of trying to explain what was wrong with me when I didn't even know myself. Social situations, phones, restaurants and drive-ins were a nightmare for me. So my kids and my friends did all the talking for me outside of work.

I moved back to NY to be near my family again and worked some low paying jobs for a few years, but after some tough NY winters and my children now grown, I moved back to Florida. I got a job at the back office of a mutual fund company. Here I didn't need to be on the phones or deal with customers and I had great medical benefits. As a result, I started seeing doctors about my voice again.

An ENT referred me to an otolaryngologist in Tampa who was treating SD with Botox. I had my first shot in 2002. After 18 years, I finally had a voice again that wasn't shaky and hoarse, even though it was only temporary.

I had never heard anyone else with a voice like mine, so my doctor recommended I attend a meeting of the Tampa Bay Spasmodic Dysphonia Support Group. It was their summer picnic meeting so I went and actually shed a few tears. For the first time ever, I heard people with SD speak and some had voices much worse than mine. I have been part of that group ever since and made friendships that have not only sustained me but have helped me find the confidence I needed to eliminate most of the self-consciousness I felt about my voice. These are my people.



In 2010, I was invited by the NSDA to be an advocate with the Dystonia Advocacy Network. I went to Washington DC to present a Distinguished Public Service Award to a Congressman from my Florida District. This was such an honor for me. It gave me self-confidence and impacted my self-esteem in a very positive way. Public speaking was never my forte, but now I was learning to speak about important things. The NSDA gave me so much guidance and treated me with such respect. Two years ago the NSDA recommended me to become the Chair of the Dystonia Advocacy Network. It is such an honor for me to hold this post and something I never would have expected to happen to me in my lifetime. I am the first person with SD to hold this position.

Advocacy is very important because while there is no cure, research can help improve treatment options, and advocacy can help fund future research. All of us need to speak up for this. Dystonia does not get a lot of recognition and so it is important to talk to legislators and get the information out there. And maybe, in the future, there will be more options and better treatments for all of us afflicted with this voice disorder.

It was the NSDA, the Tampa Support Group and my participation in the Dystonia Advocacy Network that has helped to improve my self-esteem and to feel confident again. Assuring that the NSDA can continue to help others is so very important to me. This is why I included the NSDA in my will.

Gifting Retirement Assets

If you are like most people, you probably will not use all of your retirement assets during your lifetime. Because 60%-70% of your retirement assets may be taxed if you leave them to your heirs at your death, donating part or all of your unused retirement assets, such as your IRA, 401(k), 403(b), pension or other tax-deferred plan, is an excellent way to make a gift to the National Spasmodic Dysphonia Association and help further our Vision and Mission.

Donating During Your Lifetime

According to Fidelity Charitable*, in order to donate retirement plan assets during your lifetime you would:

1. Take a distribution from the retirement account,
2. Include the distribution in your income for that year,
3. Account for any taxes associated with the distribution, and
4. Contribute the cash to the charity.

People who are 72 or older can contribute up to \$100,000 from their traditional IRA directly to a charity and avoid paying income tax on the distribution. This is known as a qualified charitable distribution which counts toward your required minimum distribution(RMD) but is not included in your adjusted gross income (AGI). This is limited to traditional IRA's and a tax professional should be consulted when considering this option.

Donating as Part of an Estate Plan

There can be significant tax advantages to donating retirement assets to charity as part of an estate plan. When done properly, charitable donations of retirement assets can minimize the amount of income taxes imposed on both your heirs and your estate.

Donating an IRA to Charity Upon Death

When you name a charity as a beneficiary to receive your IRA or other retirement assets upon your death rather than donating retirement assets during your lifetime, Fidelity Charitable says the benefits multiply:

- Neither you, your heirs, nor your estate will pay income taxes on the distribution of the assets.
- Your estate will need to include the value of the assets as part of the gross estate but will receive a tax deduction for the charitable contribution. This can then be used to offset the estate taxes.
- Because charities do not pay income tax, the full amount of your retirement account donation will directly benefit the NSDA
- It's possible to divide your retirement assets between charities and heirs. This gives you have the opportunity to support a cause you care about and insure your voice is heard, while still providing for those you love.

Making a Gift of Retirement Assets

To leave your retirement assets to the NSDA you will need to complete a beneficiary designation form provided by your retirement plan. If you designate the NSDA as beneficiary, we will benefit from the full value of your gift because your IRA assets will not be taxed at your death. Your estate will benefit from an estate tax charitable deduction for the gift. The retirement assets will then pass directly to your beneficiaries (including charities) without going through probate. If you are married, ask the plan administrator whether your spouse is required to consent. If required but not done, this could result in a disqualification of the charity as your beneficiary.

*<https://www.fidelitycharitable.org/philanthropy/bequests.shtml>



Gifts of Life Insurance

Life insurance is an excellent tool for making charitable gifts. You may find that the most tax-effective way to donate life insurance is to transfer the policy so that the charity becomes the owner and beneficiary. You are entitled to an immediate charitable deduction for income tax purposes. If you continue to pay the premiums, each payment is also a deductible charitable donation. The policy is removed from your estate, which can mean significant estate tax savings.

Benefits of Gifting Life Insurance

- You receive a charitable income tax deduction
- If the NSDA retains the policy to maturity, you can receive additional tax deductions by making annual gifts so that we can pay the premiums.
- If the NSDA cashes in the policy, you will be able to see firsthand how your gift supports our work.
- If we retain the policy to maturity, or you name us as a beneficiary, once the policy matures, the proceeds of your policy will be paid to our organization so that we can use the proceeds to further our work.

Making a Gift of Life Insurance

To make a gift of life insurance, please contact your life insurance provider, request a beneficiary designation form from the insurer and include the NSDA as the beneficiary of your policy.

Charitable bequests are well-kept secrets. Few people realize legacy gifts support philanthropy today and the good work that will happen tomorrow.

Because of the generosity of people like you, the NSDA will be able to continue to provide support, awareness and research opportunities, today and tomorrow, for people living with spasmodic dysphonia and related voice disorders!

Take these Steps When Making a Planned Gift

Being active in making the decisions about how your estate is distributed will insure that what's important to you is honored.

1. Contact the National Spasmodic Dysphonia Association for more information about your options. We can provide you with sample language for bequests. You can contact us at 800-795-6732, e-mail us at NSDA@dysphonia.org, or go to our website at www.dysphonia.org. This will not only inform the NSDA of your intentions, but gives us the opportunity to thank you and recognize your generous gift.
2. Contact your attorney or financial advisor. Let them know you are considering a planned gift to the National Spasmodic Dysphonia Association. They can assist you in the determining what type of gift best suites your personal and financial circumstances.
3. Be sure to talk to your family and friends about your plans and personal wishes in addressing family needs as well as your legacy gifts.
4. Know you have made a lasting gift that will impact future generations!

Thank you for your continued support of the National Spasmodic Dysphonia Association and we hope you will consider becoming part the Legacy Society!



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