



RARE INSIGHTS

Building A Stronger Financial Future





Thank you for including us in your story! This Global Genes RARE Insight offers practical steps, tips, suggestions, and resources for: **Building a Stronger Financial Future.** This Insight is one in a series we are creating in response to the need for more information about adjacent issues that affect the medical needs of the RARE community. The Insights offer an introduction to a subject, not a conclusion. We believe the real-world knowledge the Insights provide will make it much easier for you to find the information you are seeking about a topic. More importantly, you should know you are not alone in your search for answers. We are in this together! ■



Paper and pen indicate an interactive exercise

Caveman Wisdom: Considerations for Financial Planning

The parental rebuke “money doesn’t grow on trees,” is as true today as it was when a caveman grunted it to his children in 33 B.C. Therefore, absent the money tree, building a stronger financial future for your family is up to you!

Regardless of your circumstances or tax bracket, financial planning has many benefits. Listed are typical financial goals many people have. Place a check-mark next to the goals that match yours:

- ☐ To afford the best healthcare insurance options available for my family
- ☐ To cover the cost of unexpected medical needs (severe injuries, chronic illnesses, debilitating diseases, etc.)
- ☐ To have enough savings to stay afloat if there is a loss of primary income due to unemployment, accident, or illness
- ☐ To build a nest egg for a comfortable retirement
- ☐ To invest in career advancement training, continuing education, or business opportunities
- ☐ To provide elder care for parents
- ☐ To guarantee long-term care for a special needs child
- ☐ To buy a home, condo, or vacation property
- ☐ To invest in stocks, bonds, and other financial products
- ☐ To assist children with college tuition
- ☐ To pay for life events (weddings, child birth, and end of life needs)
- ☐ To afford leisure activities (vacations and hobbies)
- ☐ To pay for medical rehabilitation services
- ☐ To pay for assisted living/hospice care
- ☐ To live like a member of the Royal Family of England

Money Talk: Unpacking Key Terms

Annuity is a contract for a financial growth product between you and an insurance company. Annuities are designed to meet retirement and other long-range financial goals. They typically offer tax-deferred growth of earnings and may include a death benefit that will pay your beneficiary a specified minimum amount, such as your total purchase payments.

Bankruptcy is a legal declaration that a person or corporation is unable to pay their debts and therefore needs to have the debt forgiven or reorganized. In bankruptcy proceedings the debtor's assets and debts are evaluated. After the evaluation the debt is repaid according to the debtor's ability to pay; what the creditors will accept; and what the court and the law decide upon.

Benefactor is a person who gives some form of financial help to a beneficiary (a person, group or organization), often gifting a monetary contribution in the form of an endowment.

Beneficiary is a person who will receive the benefit of property from an estate or trust of a benefactor, through the right to receive a bequest or to receive income or trust principal over a period of time. Court-appointed guardians are appointed by a court to be guardians of property or

conservators. Guardians have the duty and the power to make financial decisions on someone's behalf.

Estate planning is the process by which an individual designs a strategy and executes a will, trust agreement, power of attorney, and other documents to provide for the administration of his or her assets upon his or her incapacity or death. Tax and liquidation planning are part of this process.



Family trust is a trust established to benefit an individual's spouse, children or other family members. A family trust is often the bypass trust or credit shelter trust created under a will.

Fixed expenses are ongoing expenses that generally cost the same from payment to payment. They are most often paid on a regular basis, such as monthly, quarterly, or annually. Examples of fixed expenses are: a mortgage/rent, vehicle loan payments, and insurance premiums. Healthcare power of attorney is a document that appoints an individual (an "agent") to make healthcare decisions when the grantor of the power is incapacitated. Also referred to as a "healthcare proxy."

Insurance trust is an irrevocable trust created to own life insurance on an individual or a couple and designed to exclude the proceeds of the policy from the insured's gross estate at death.

Letter of intent / memorandum of intent is a letter indicating that the writer has the serious intention of doing something, such as signing a will. But it does not constitute either a promise or a contract.

Life beneficiary is an individual who receives income or principal from a trust or similar arrangement for the duration of his or her lifetime.

Living will is a written document that allows a patient to give explicit instructions about medical treatment to be administered when the patient is terminally ill or permanently unconscious; also called an advance directive.

Marital deduction is an unlimited federal estate and gift tax deduction for property passing to a spouse in a qualified manner. In other words, property transfers between spouses generally are not taxable transfers because of the marital deduction. Power of attorney (POA) provides a person who has been designated as such, with the legal power to make decisions about the money, property, and medical directives for someone else.

Principal is the property (money, stock, and real estate) contributed to or otherwise acquired by a trust to generate income and to be used for the benefit of trust beneficiaries according to the trust's terms.

Probate is a court process that proves a will of a deceased person is valid, so their property can in due course be re-titled or transferred to beneficiaries of the will.

Social Security Disability Insurance (SSDI) is a social insurance program under which workers earn coverage for benefits, by working and paying Social Security taxes on their earnings. The program provides benefits to disabled workers and to their dependents.

Social Security Insurance-Child (SSI-C) is a social insurance program for a person who is neither married (as determined by Social Security) nor head of a household and: is under age 18; or under age 22 and is a student regularly attending school (as determined by Social Security).

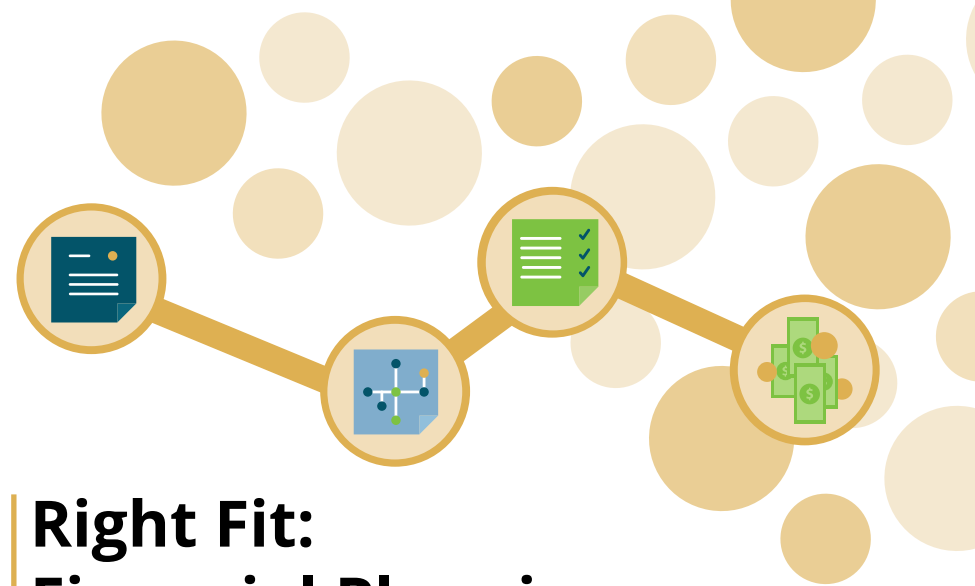
Special needs trust is a trust established for the benefit of a disabled individual that is designed to allow him or her to be eligible for government financial aid by limiting the use of trust assets for purposes other than the beneficiary's basic care.

Trust is a legal instrument comprised of a variety of assets intended to provide financial security benefits to an individual (usually a child or grandchild) or a nonprofit organization (charity). A trust fund gives the benefactor "control from the grave," regarding when, how and to whom the fund is distributed.

Trustee is the person(s) who is designated to oversee a revocable living trust. When ownership of some or all money and property has been transferred to a trust, the person named as a trustee has the power to make decisions about the contents of the trust.

Variable expenses are expenses that vary from day-to-day. Examples of variable expenses are buying clothes; picking up the tab for happy hour; groceries; and poker night losses.

Will is a legal document that expresses a person's final wishes as to how their property is to be distributed at death. It also names the person (executor) who has been designated to manage the estate until its final distribution. ■

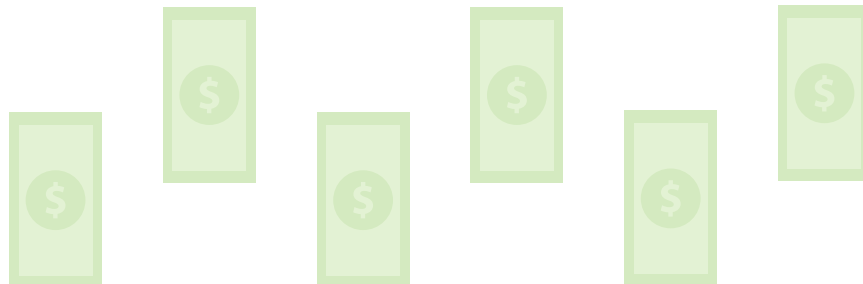


Right Fit: Financial Planning

There is not a one-size-fits-all answer to financial planning. To create a plan that is the right fit for your family, begin with a vision of your financial goals, so that you can share it with your financial team.

Here is a list of financial planning suggestions from the field. (*Words in bold are defined in the Key Terms section.*)

- Do your research. The devil really is in the details when it comes to the benefits and the risks of a 401(k) retirement plan, pension, certificates of deposit, savings, stocks and bonds, home ownership, life insurance, an **annuity** and other financial growth products.
- Home ownership can offer long-term financial benefits to you and your **beneficiary**. Do your homework before you purchase a home. Take time to assess more than mortgage interest rates and closing costs. Find out how much mortgage insurance cost, the application fees, and how the interest rate might change over the life of the loan.
- Life insurance riders are forms of additional or supplemental life insurance coverage. They can be purchased as add-ons to your main life insurance policy, to provide extra coverage for a number of specific situations like: payment of personal debts, cost of living changes, college tuition payments, and disability income.
- Designate two people to fulfill the duties of **power of attorney (POA)**. Designating two people minimizes potential conflict of interest decisions that can happen when only one person is the POA. Choose someone to be your **healthcare power of attorney** and choose another person to have power of attorney over your finances.



- Designate a trust company as the **trustee** of a **trust fund** rather than a person. Two benefits of designating a trust company as the trustee are: firstly, they have the legal resources to fight claims against the estate; secondly, legal disputes amongst family members about the estate are minimized.
- Tax advantages. On average Americans lose about 35 percent of their earnings to taxes. For many people taxes are their single largest family expense. One option for reducing taxes and keeping more of what you earn are a variety of tax deductions for having a home-based business.
- To receive **Social Security Disability Insurance (SSDI)** benefits, a person must meet the Social Security Act's definition of disability. A person is deemed disabled under the Act if he or she is unable to work due to a severe medical condition that has lasted, or is expected to last, at least one year or result in death. The person's medical condition must prevent him or her from doing work that he or she did in the past, and it must prevent the person from adjusting to other work.
- People age 18 through 64 who are receiving Social Security disability benefits can participate in SSA's Ticket to Work program. The program allows a person to receive free employment support services, and to take advantage of incentives that make it easier to work and to still receive benefits like healthcare. In some circumstances the person can receive cash benefits from Social Security, and are also protected if there becomes a need to stop working due to disability.
- Should you have a **will**, a **trust**, or both? Ask an estate attorney to explain how a will and trust differ. Popular benefits of a trust are: it eliminates **probate** court on an estate; it can provide some tax benefits; and unlike a will, the details and distribution of a trust are private because it avoids the probate court process.
- If you have the desire to provide equitably for a special needs child, his or her siblings, and other heirs make sure to factor this into your long-term financial planning strategy.
- Consult with financial and legal experts or check with the Better Business Bureau before entering into new or unconventional financial ventures.
- Enforced by the Federal Trade Commission (FTC) the Funeral Rule makes it possible for you to choose from a funeral home, only the goods and services you want or need; and to pay only for those you select, whether you are making arrangements when a death occurs or in advance. ■



Goal Tending: 5-in-30 Interactive



Done in manageable, consistent, steps, building a stronger financial future does not have to be a time hog. List your top 5 financial goals, in order of preference, in 30 minutes or less.

1. _____
2. _____
3. _____
4. _____
5. _____



Dollars & Sense

The old-school way of paying bills – checks sent by snail mail is being replaced by the convenience of electronic payments on mobile devices and online. But no matter how you pay your bills, there will always be costs for the caveman survival needs of food, shelter, fire, stonewashed jeans, and Sunday Funday.

Use these steps to create a basic budget worksheet, and then share it with your family and your financial team. We don't judge...if your \$5 a day coffee is a must-have, by all means list it as a fixed expense instead of a variable expense. (*Words in bold are defined in the Key Terms section.*)

1. Create a budget based on your net pay and other income sources including: alimony, child support, **SSI-C**, financial settlements, **annuity** payments, etc. But, remember to subtract your deductions for Social Security, taxes, 401(k) and flexible spending account allocations when creating a budget worksheet.
2. Keep track of and categorize your spending. This tracking makes it easier to know where, if necessary, you can make adjustments. First list your **fixed expenses** and then list your **variable expenses**.
3. Refer back to the goals you listed in the **Goal Tending 5-in-30 Interactive** before you analyze the information you've tracked for your budget worksheet. Determine which of your listed goals are short-term goals and which are long-term goals. Short-term goals should, ideally, not take longer than a year to achieve. Long-term goals, such as buying income property, may take years to do.
4. Use your variable and fixed expenses to get an idea of what you spend money on monthly, quarterly, and yearly. See where you can redirect money you habitually spend on variable expenses (restaurants) toward achieving one of your top five financial goals.
5. Review your budget monthly when you pay your bills; doing so will help you to stay motivated about your financial goals and how to achieve them.
6. Get children involved with filling in the household budget worksheet. Use it to show them how fixed expenses and variable expenses affect the "money doesn't grow on trees" spending decisions you make daily. ■



Financial Selfie: Checkup Questions

Tilt your head, raise your chin, lower your eyes, smile wide—not too wide, are just a few tips for how to take selfies like a celebrity. In other breaking news, your answers to these questions can help you see your financial picture more clearly.

- ✓ How far will your savings and unemployment compensation or workmen's compensation benefits go to cover your family's fixed expenses if there is a short-term (a year or less) loss of salaried income?
- ✓ Would your current savings, investment dividends, and disability insurance benefits cover your long-term (a year or more) financial needs if there is an extended loss or permanent reduction of salaried income?
- ✓ If you have a special needs child, which government assistance programs have you researched to determine if he or she qualifies for long-term financial and medical assistance in your state?
- ✓ If there is a loss of the breadwinner's salaried income due to his or her death or due to medical reasons, what financial resources do you currently have to meet your family's fixed expenses for a lifetime?
- ✓ What singular thing (stock investments, income property, a better paying job, etc.) do you believe will most quickly help you to reach your long-term financial goals?
- ✓ Which specific items in your current financial portfolio do you believe will provide the most long-term financial security to your life beneficiaries?
- ✓ If the majority of your investments are in the stock market via a 401(k) employee retirement account, what is your backup plan for your long-term financial growth if the stock market crashes or you become unemployed?

Special Needs: 10-Who-Knew?! Tips

If you have a child with special needs your financial goals most likely include the desire for peace of mind regarding financial care for your dependent today and in the distant future. Listed are legal and government tips that are helpful to know for making special needs financial decisions.

1

In most states, a child who gets SSI-Child benefits can get Medicaid to help pay medical bills. And In some cases, a child may be eligible for Medicaid while in an institution, but not be eligible when living at home either because of their parent's income and resources or of other income.

2

The Uniform Transfers to Minors Act is a law in some states that provides a convenient means to transfer property to a minor. A benefactor designates another adult person known as a "custodian" to receive and manage property for the benefit of a minor. Although the legal age of adulthood in many states is 18, the benefactor may authorize the custodian to hold the property until the minor reaches age 21.

4

If you need to hire someone to assist you with the care of a special needs family member, you may be able to take the Child and Dependent Care Credit on your federal tax return. This credit can save you a lot of money because it reduces your tax bill on a dollar-for-dollar basis. Qualifying requirements and instructions on how to apply for the credit are available on the IRS.gov website.

3

At a state's option, children under age 18 who need institutional-level care and live at home may keep Medicaid eligibility while getting home care, if that care is less costly to the government. Even if the child is not eligible for SSI-Child benefits, the child still may be eligible for Medicaid under other state rules. For the most current information check on Medicaid eligibility for your state.

5

Babies are presumed healthy at birth; therefore, purchasing life insurance for a newborn can likely be done without medical exams. There are long-term financial benefits for buying life insurance for children. One benefit is the child will already be covered if he or she is diagnosed with a chronic medical condition later in life.

6

Know how much money you can leave your dependent. Currently, the federal law says if you leave over \$2,000 to a person with a disability he/she automatically loses eligibility for most government benefits and services. And remember, taxes may be assessed on money the dependent receives.

7

Calculate comprehensive expenses for a lifetime of care by projecting monthly income needs. Also, take into account the impact of inflation and how it will likely affect the cost of providing for the child's basic and specialized needs for years to come.

8

Life insurance is potentially free of inheritance and estate taxes. To determine what the most appropriate type of life insurance is to fund your dependent's special needs trust consider: your financial goals; your dependent with special needs; and your larger family picture.

9

To be able to provide for the long-term financial needs of your dependent, your spouse, and yourself, include a "three-person-retirement" strategy in your financial planning.

10

A memorandum of intent documents a parent's knowledge of a dependent child's needs. The purpose of writing a memorandum is to give future caregivers and/or guardians information that you believe is critical for providing the dependent with care that is consistent with what he or she is accustomed to.





Professional Partnership Tips: Financial Planners

Financial planners come from a variety of industries (insurance, investment firms, banking, etc); and they specialize in different financial products and services. Parents with special needs children emphasize the importance of partnering with planners who have special needs financial planning experience and, preferably, a personal connection with special needs care.

Expect that some financial planners will want to review your entire financial situation and then present you with a plan that is specific to achieving your financial goals. Some financial planners sell investments and other financial products like insurance, while others only prepare financial plans.

There are some planners who will only recommend the products they sell, but services they offer can vary significantly. Some create comprehensive plans that include every area of your financial life (debt, savings, investments, insurance, estate planning, retirement reserves, taxes, etc.). Others may only focus on what they specialize in such as insurance or securities.

One trustworthy way to find a financial planner is by asking family, friends, and others in your immediate circle for recommendations. Other reliable sources for finding a planner are are your employer, labor union, tax preparer, and members of civic and religious organizations.

Listed are typical questions to ask a financial planner before you hire him or her:

- ✓ What experience do you have working with people whose financial circumstances are similar to mine? (And more specifically with special needs planning?)
- ✓ What licenses do you currently hold?
- ✓ Are you registered with a state, the SEC, or FINRA?
- ✓ What are your special areas of expertise?
- ✓ How long have you been with your current firm?
- ✓ What investment products and services do you most often recommend to your clients? Why?
- ✓ Are there any products or services you don't recommend? Why?
- ✓ How much will I have to pay for your services?
- ✓ Do you or your firm impose any minimum account balances?
- ✓ How frequently will we meet to discuss my portfolio?
- ✓ Who else in your office will handle my account?
- ✓ Have you ever had a professional license revoked?

Listed are typical questions a financial planner may ask you to answer:

- ✓ How much money do you have in savings and investment accounts?
- ✓ How is that money distributed (bank/credit union, certificates of deposit, individual securities, etc.)?
- ✓ How much can you add to these accounts annually?
- ✓ What are your specific financial goals (short-term and long-term)?
- ✓ Do your goals have specific time frames (short-term/long-term)?
- ✓ How much investment risk are you comfortable taking?
- ✓ What other investment professionals are you working with?
- ✓ Do you have life insurance? If so, how much?
- ✓ Have you ever worked with a financial planner before? If so, what was that experience like?

Remember to:

1. Ask for a copy of the account agreement, fee structure, and any other documents you would be required to sign if you hire the planner.
2. Take the documents home and read them carefully to make sure they reflect your understanding of the terms you discussed in the meeting.
3. Use the documents to make comparisons to other financial planners you are considering hiring. ■



10-to-Know: Money Management Tips

Even a modest amount of seed money can provide a solid foundation for financial growth. From a cheaper cup of coffee to home ownership, these tips may give you some new ideas about how to better manage your money.

1. Talents and hobbies can be fun and lucrative sources of additional income and may also meet the criteria of some tax deductions. Who'da thunk it? Your passion for carving salt and pepper shakers out of deadwood could be the start of a profitable home-based business.
2. When buying a home, factor in the cost of having to purchase services from realtors, title companies, and insurance providers. In light of the options available for these services, consider and evaluate their costs to get the best terms possible.
3. Ditch your \$5 a day cup of coffee for a \$2 cup, and you'll save upwards of \$600 a year. Brew your joe at home, and the savings can more than double to a whopping \$1,300 a year! If breaking up with your favorite barista is hard to do, try it a couple of times a week to start. Put the cash you save on the ditch days into your own "tip" jar at home for a month to determine if it's worth the sacrifice.
4. Pay it forward. After you pay off a credit card, auto loan, or your in-laws apply that payment to another debt or pay it forward to a savings account.
5. April is Financial Literacy Month. In addition to preparing your taxes, choose one weekend in April, annually, to review service provider agreements. Assess whether or not to renew, cancel, or renegotiate contract changes for cable, mobile phone plans, appliance warranties, auto insurance, and similar services.
6. Save 50 percent of pay raises, company bonuses, and unearned cash of any amount—yes, even \$10 bingo winnings. This rewards and

savings habit is a win-win; there's some extra cash in your budget and a continued growth of your savings account.

7. Change agents! Bank debit card change transfer programs round up each debit card purchase you make to the nearest dollar, and then automatically transfers the extra change into your savings account. And some programs will even match, up to a yearly maximum, the amount of change transferred.
8. Smartphone technology puts money management apps in the palm of your hand. Services include everything from text alerts about changes to your bank balance to making investments in the stock market for you.
9. Smarty-pants college plan. A 529 Plan is an education savings plan operated by a state or an educational institution. Created by the IRS to give parents a place to save money over time for future college costs, one of the popular benefits of a 529 Plan is contributions to it do not have to be reported on your federal tax return.
10. Smarter schooling? In addition to a better academic environment for their children, many homeschool advocates are also motivated by the money they save. While there are homeschooling costs: teaching curriculums, tests, and other supplies, some homeschoolers calculate these costs to be significantly less than money spent yearly, per child, on school clothes/uniforms, lunches, yearbooks, and extracurricular school activities. ■



Self-Rewards: 5-in-30 Interactive

Earlier you listed, in order of preference, your top 5 financial goals. Now in 30 minutes or less, list 5 ways you will reward yourself for making real progress on your goals.



1. _____

2. _____

3. _____

4. _____

5. _____



Next Steps: Ready Set Go!

1. Use the information in this Insight to find other resources that can help you and your family to create a stronger financial future. And make sure to think about “lifetime care” and “quality of life” issues when planning for a special needs dependent.
2. Enlist the services of a financial planner, CPA, estate attorney, and a life insurance professional to help your family with its financial planning needs. But always remember you are the expert about your special needs dependent.
3. Take this Global Genes Insight with you to meetings with your financial team to make it easier to ask questions about your specific financial and legal needs.
4. Ask your legal and financial advisers to recommend other helpful resources that may be outside of their areas of expertise, but are pertinent to your financial plan.
5. Reward your efforts a long the way! ■

Resources

Academy of Special Needs Planners (ASNP) consists of special needs planning professionals such as attorneys, financial planners and trust officers that assists them in providing the highest quality service and advice to persons with special needs and to their families. Contact us for more information at specialneedsanswers.com

Consumer Financial Protection Bureau (CFPB) is a U.S. government agency that makes sure banks, lenders, and other financial companies treat you fairly. Learn more at consumerfinance.gov about how the CFPB can help you.

Federal Trade Commission (FTC) protects consumers by stopping unfair, deceptive or fraudulent practices in the marketplace. We conduct investigations, sue companies and people that violate the law, develop rules to ensure a vibrant marketplace, and educate consumers and businesses about their rights and responsibilities. Contact FTC.gov for more information about our services.

Mymoney.gov is a product of the Congressionally chartered Federal Financial Literacy and Education Commission, which is made up of more than 20 federal entities that are coordinating and collaborating to strengthen financial capability and increase access to financial services for all Americans.

Social Security Administration (SSA) is a U.S. government agency that provides financial services connected to Social Security Disability Insurance (SSDI). Contact us at SSA.gov for detailed information on eligibility requirements and SSA definitions of disability.

Special Needs Alliance is a national, non-profit organization committed to helping individuals with disabilities, their families and the professionals who serve them. Many of our member attorneys have family members with special needs. Contact us for more information at specialneedsalliance.org.

U.S. Securities and Exchange Commission (SEC) protects investors; maintains fair, orderly, and efficient markets; and facilitates capital formation. The SEC strives to promote a market environment that is worthy of the public's trust. Contact SEC.gov for more information on the SEC's services.

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