



Midwest Special Needs Trust
FY 21 Annual Report
July 1, 2020 - June 30, 2021

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Midwest Special Needs Trust Mission and Purpose

To provide compassionate professional special needs trust administration services to enhance the lives and foster the ability of people with special needs.

Midwest Special Needs Trust is an organization with a proud and distinct history. Established in 1989, the Missouri Family Trust (MFT), doing business as Midwest Special Needs Trust (MSNT), is a nonprofit 501(c)(3) corporation authorized by Missouri statute to administer special needs trusts for individuals with disabilities. MSNT is not a part of state government and does not receive state or federal appropriations. MSNT is governed by a nine member Board of Trustees and its operations are conducted by staff under the direction of the Board of Trustees. Board members are appointed by Missouri's Governor with the advice and consent of the Senate. Six Board members are individuals who have a family member with a disability. Three Board members are individuals with expertise in business. Board members serve without compensation and are appointed to 3 year staggered terms. The composition of the Board is uniquely crafted to reflect our commitment towards a desired future, envisioned and articulated by the population we serve.

Individuals with disabilities and their families are often living within strict financial parameters and normally would not otherwise have access to special needs trusts to protect their public benefits. MSNT accepts modestly sized trusts and bases enrollment fees on a sliding scale for the purpose of providing an affordable pooled trust administration option.

MSNT also administers the Charitable Trust of the Missouri Family Trust, awarding grants to Missourians with disabilities who are living below the federal poverty level. The Charitable Trust program focuses on addressing unmet needs not covered by public benefits or other community resources. Grant funds are also available as approved by the Board of Trustees to assist with natural disasters and extreme emergencies. Awarding Charitable Grants makes a big impact on the community and is one of the many facets of our work that makes staff and the Board proud to represent MSNT.



Midwest Special Needs Trust



Executive Summary

This report highlights the achievements of Midwest Special Needs Trust (MSNT) during FY 2021 (July 1, 2020 – June 30, 2021) and outlines future opportunities and goals for sustainability and growth. Each year, MSNT pauses for reflection and establishes priorities for the coming year. The FY 2022 Annual Business Plan is the compass used to set the overall direction for continuity of operations, resource management and performance measurement.

Some notable achievements, this past year included the following:

- MSNT staff remained agile during a once in a century challenge – a global pandemic.
 - Work continued without any harm or delay to a single beneficiary, all operations moved to an unprecedented way of doing business remotely. Staff rallied to assume additional duties.
 - Leadership continuously analyzed the shift to hybrid work to ensure individual and organizational effectiveness.
 - A return to the office plan was carefully crafted and communicated to maximize staff safety and utility of office space. Using a gradual, phased approach all staff returned to the office.
- MSNT accomplished a smooth transition from Simmons Bank to True Link Financial Services, thereby providing enhanced services to Life Beneficiaries. True Link was founded to provide fiduciaries of pooled special needs trusts robust software and customized investment management.

Benefits of the transition include:

- Access to technology based special needs trust administration and investment services, including specific software to manage disbursements and reporting.
 - Life Beneficiary and responsible party access to the True Link online portal to view account balances, view transaction history, access account statements and submit disbursement requests.
 - Significant decrease in tax preparation fees for first party and third party irrevocable trusts (starting with 2021 Tax Returns).
 - Age related investment planning that balances longevity and the individual circumstances of the Life Beneficiary (MSNT investment directed trusts).
 - Elimination of monthly True Link Prepaid Visa Card transaction fees for Life Beneficiaries.
 - Lowered minimum sub-account balance from \$1,000 to \$500.
- MSNT awarded 6 COVID-19 Relief Grants totaling \$120,000 for the express purpose of supporting agencies that provide services to individuals with disabilities and help them remain solvent during the COVID-19 crisis.

- MSNT’s Charitable Grant Program earned a 2021 Gold Seal of Transparency by Candid, formally known as GuideStar, who reviews the mission, legitimacy, impact, reputation, finances, programs and leadership structure of non-profit agencies. This compilation of information helps donors make informed decisions about which non-profit agencies they want to support.

- Dedicated efforts to serve low to middle income individuals and families who might otherwise be unable to establish a trust by accepting small trusts as little as \$1,000, net of the enrollment fee and keeping fees affordable and utilizing a sliding fee scale for enrollment fees:
 - MSNT discounted enrollment fees for 63% of Life Beneficiaries.
 - The average size of the 49 new sub-accounts in FY 21 was \$ 21,158.43.
 - The average balance of active sub-accounts as of 6/30/21 was \$44,732.
 - MSNT serviced 2,441 sub-accounts since 1989.

- MSNT processed 3,794 permissible distributions of over \$ 4.0 million for the benefit of Life Beneficiaries while protecting eligibility for important public benefits.

- MSNT continued to expand the True Link Prepaid Visa Card program to offer an alternative to paper checks for Life Beneficiaries, as appropriate.

- Two staff completed the Virginia Commonwealth University Introduction to Social Security Disability Benefits, Work Incentives, and Employment Support Programs web course.

- All staff completed Mental Health First Aid Training conducted by the Missouri Institute of Mental Health/Department of Mental Health.

- One staff completed Cannon Financial Institute’s Cannon Trust School Parts I and II.



MSNT Milestones

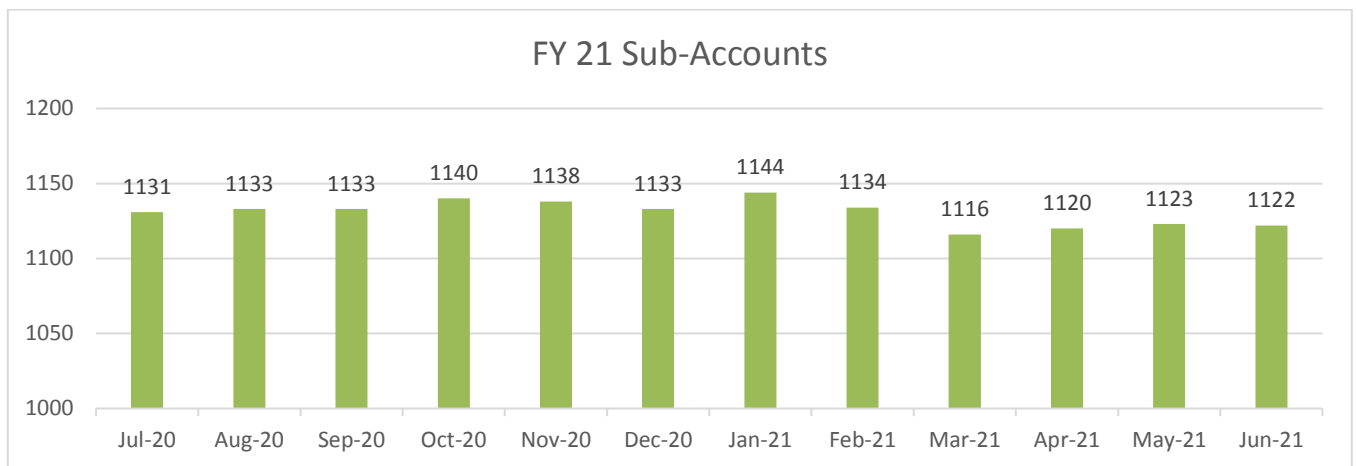
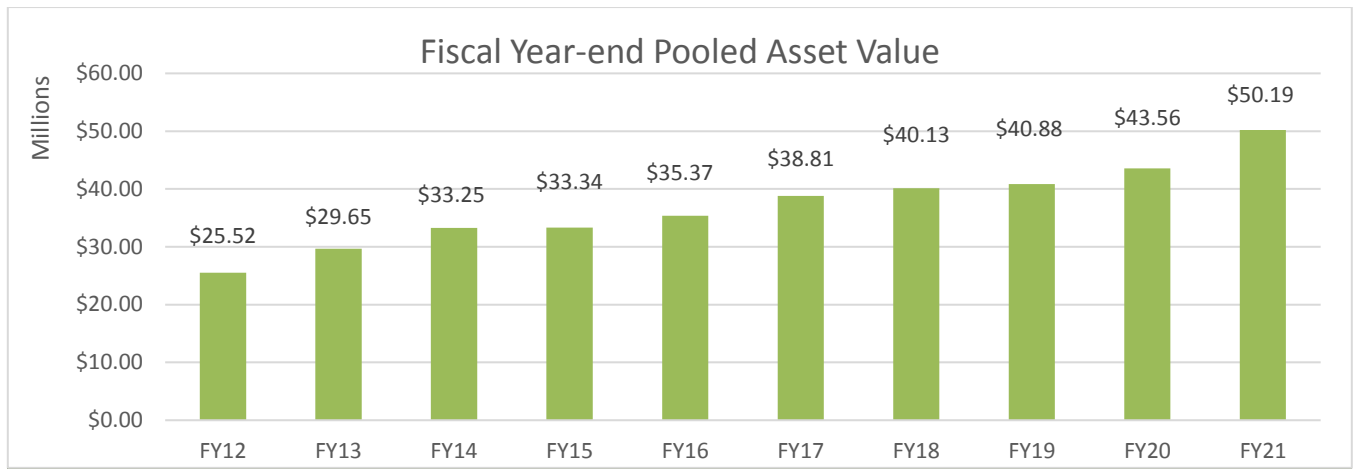
- In 1989, Missouri Family Trust was created by Missouri state statute.
- In 1990, MFT was incorporated as a not-for-profit corporation.
- In 1991, MFT opened the first trust account.
- In 1993, federal statute was passed that defined and exempted first party special needs trusts as assets, protecting eligibility for public benefits.
- In 2006, MFT began doing business as Midwest Special Needs Trust, expanding its service area to include the states contiguous to Missouri.
- In 2011, MSNT state statutes were substantially updated.
- In 2012, MSNT moved to independent leased space, improving security, efficiency and effectiveness in daily operations.
- In 2013, MSNT trust accounts surpassed 1000 active trusts.
- In 2015, MSNT expanded its offices to accommodate staff growth.
- In 2015, a dedicated employee was hired to devote full time attention to the Charitable Trust program.
- In 2016, MSNT rebranded with a new logo, marketing materials and website.
- In 2017, MSNT successfully completed a Social Security Administration review and hired an additional Trust Specialist.
- In 2018, MSNT added the True Link Card program and presented to the Hong Kong government on special needs trusts and MSNT operations.
- In 2019, MSNT added another Trust Specialist and presented to the 5th World Congress on Adult Guardianship in Seoul, South Korea on special needs trusts and MSNT operations.
- In 2019, MSNT hired an Associate Director.
- In 2020, MSNT hired an Operations Specialist.
- In 2020, MSNT staff anticipated and overcame challenges to seamlessly transition to providing trust services remotely due to the COVID-19 global pandemic.
- In 2020, MSNT transitioned to True Link Financial Services.
- In 2020, MSNT awarded 6 COVID-19 Relief Grants totaling \$120,000.
- In 2021, MSNT hired a Trust Specialist I and Trust Specialist II for a total of 10 staff.
- In 2021, MSNT's Charitable Grant Program earned a 2021 Gold Seal of Transparency by Candid, formally known as GuideStar.



Overview of MSNT Historical Performance

Midwest Special Needs Trust continues to provide special needs trust administration services for people with disabilities and their families living in Missouri and the surrounding states (Arkansas, Illinois, Iowa, Kansas, Kentucky, Nebraska, Oklahoma and Tennessee).

In the last decade, the number of trusts administered by MSNT has grown, and the value of trust assets has doubled. Trends are depicted in the following charts for both asset value and active sub-accounts.





FY 2021 in Review

As of June 30, 2021, MSNT was administering 1122 active sub-accounts with an asset value of \$50.2 million collectively in pooled accounts. These numbers reflect growth from new deposits as well as investment earnings, which like the value of investments, can fluctuate depending on market performance and economic conditions. These numbers need to be considered in the context of two significant developments, one, in the federal Internal Revenue Code and, two, by the Missouri Department of Social Services in the MO HealthNet (Medicaid) program:

- The establishment of the ABLE accounts allowing another public benefit protective financial tool for up to \$15,000 a year.
- The passage of House Bill 1565 provided an increase of the Missouri Medicaid asset limit from \$1,000 to \$5,000, over a period of (5) years.
- Beginning in fiscal year 2022 and each successive fiscal year, a cost of living percentage will be measured and applied. Therefore, it is expected that the asset limit will continue to increase.

These federal and state policy changes are to be commended and provide some much-needed relief to the populations we serve. However, providing an alternative does impact the rate of expected growth in special needs trusts.

In FY 21, MSNT continued its dedication to serve low to middle income individuals and families who might otherwise be unable to establish a trust and to its commitment to small trusts, keeping fees affordable and utilizing a sliding fee scale for enrollment fees. MSNT discounted enrollment fees for 63% of the 49 new sub-accounts for Life Beneficiaries. The average size of these new sub-accounts was \$ 21,158.43. The average of all active sub-accounts as of 6/30/21 was \$ 44,732. MSNT also opened 8 new inactive sub-accounts. This is another way MSNT helps families prepare for their future needs at very little cost.

MSNT is proud to have staff complete the following:

- Virginia Commonwealth University's Introduction to Social Security Disability Benefits, Work Incentives, and Employment Support Programs web course
- Cannon Financial Institute's Cannon Trust School Parts I and II
- The Shift from Administrative Team Member to Administrative Leader course by the American Society of Administrative Professionals
- Microsoft Office Planner 101 - Effectively Organize Tasks
- Microsoft Office Excel for Nonprofits - Data Management and Reporting

MSNT was pleased to conduct presentations for:

- Tennessee Virtual Mega Conference
- St. Louis Arc
- Council of Nephrology Social Workers of Eastern MO and Metro East
- University of Missouri-Columbia Elder Law Course

- Missouri Department of Mental Health Spring Training Institute
- Missouri Bar CLE
- University of Missouri-Columbia Personal Financial Planners Course



FY 2021 MSNT Accomplishments

- ☑ **Seamlessly continued to support proper trust administration to protect important public benefits for trust beneficiaries during a global pandemic**
 - Initiated a hybrid work model to maintain safety with a segment of staff working from home and staff working in the office, based on job functions.
 - Integrated new tools and technology to help staff work independently and collaboratively.
 - Established rigid guidelines for staff to ensure ongoing MSNT operations.

- ☑ **Staff certification/training**
 - Mental Health First Aid Certification
 - Introduction to Social Security Disability Benefits, Work Incentives, and Employment Support Programs Certificate
 - Shift from Administrative Team Member to Administrative Leader Training
 - Cannon Trust School Parts I and II
 - Planner 101 - Effectively Organize Tasks
 - Excel for Nonprofits - Data Management and Reporting

- ☑ **Large Distributions**
 - Authorized 44 requests for funds totaling \$566,134.69 to establish ABLÉ Accounts, and for personal expenses, medical, room differential, household items, and reimbursements for purchases made on behalf of Life Beneficiaries, and vehicles.
 - Authorized 11 distributions for irrevocable prepaid burial policies totaling \$30,224.71.

- ☑ **Outreach**
 - Several virtual presentations, guest lectures and speaking engagements.
 - Met with representatives from several financial trust organizations to provide information about MSNT's affordable trust services and charitable commitment.
 - Staff representation in the Columbia Chamber of Commerce Women's Network.

- ☑ **Charitable Trust**
 - Awarded 6 COVID-19 Relief Grants totaling \$120,000 to Cedar Creek Therapeutic Riding Center, Equine Assisted Therapy, ShowMe Aquatics, TREE House of Greater St. Louis, Wonderland Camp Foundation, and Exceptional Equestrians of the Missouri Valley.
 - Earned a 2021 Gold Seal of Transparency from Candid.



Special Needs Trusts - Making a Difference for People with Disabilities

MSNT staff work diligently each day to open trusts and process requests for trust distributions for important supplemental needs that are not covered by Public Benefits. During FY 21, MSNT made 3,794 permissible distributions for over \$4.0 million for the benefit of MSNT trust beneficiaries. MSNT recognizes the importance of trust assets in the lives of beneficiaries and we share the following brief stories from FY 21 as examples demonstrating how a special needs trust can enhance the quality of life for a Life Beneficiary with a disability¹.

- Mark is a 66 year old with a developmental disability. His Co-Trustee contacted MSNT indicating Mark was in dire need of a pre-paid burial policy as he was being released from the hospital to hospice. The Trust Specialist assigned to Mark's sub-account worked diligently with the funeral home and the Co-Trustee to purchase a pre-paid burial policy very quickly. The Trust Specialist was able to request a check to the funeral home within 4 hours of initial contact by the Co-Trustee. MSNT encourages the purchase of pre-paid burial policies with sub-account funds during the life of a Life Beneficiary; however, there are circumstances that constitute an emergency and Trust Specialists must work very quickly to complete the check request procedure. Thankfully, Mark was able to over-come the infection, and is doing well in the skilled facility. The Co-Trustee and other family can now be at ease knowing that a pre-paid burial policy is in place.
- Susan is a 56 year old with a physical disability. Susan is confined to a wheelchair and lives on her own with few supports. She owns her own home, which needed major modifications to accommodate her disability. Susan worked with the Trust Specialist assigned to her sub-account and a local contractor to have her home not only repaired from a leak in her bathroom and make modifications at the same time; but also, to update her ramp outside the home. Her previous ramp lead straight to the street; causing a safety risk for Susan. The new ramp wraps around the house, leading to her driveway, out of harm's way. Susan's home repairs and modifications allow her to remain safe and independent at home.
- Greg is a 20 year old with a behavioral health condition. Greg has a job, but lack of transportation seriously affected his ability to get to work. Greg and his Co-Trustee contacted MSNT about purchasing a vehicle. The Trust Specialist assigned to Greg's sub-account worked with the Co-Trustee to obtain all required information including a doctor's release to drive and driver's license. The Trust Specialist advocated for Greg to purchase a vehicle with trust funds to support his efforts to work and live on his own. The request for funds to purchase a vehicle was approved, and Greg has been successful at his place of employment.
- Lilly is a 24 year old with a physical disability. Lilly and her Co-Trustee contacted MSNT about assistance with obtaining her driver's license. Lilly had previously worked with a company that

¹ *The names and other details were changed to protect the confidentiality of Life Beneficiaries.*

does driver's evaluations and recommendations for individuals with disabilities. The Trust Specialist assigned to Lilly's sub-account worked with Lilly, the Co-Trustee and the company to obtain appropriate documentation for the cost of the evaluation. Lilly has yet to obtain her driver's license, as the evaluation had continued recommendations for her; but she is on the right track. MSNT is happy to support individuals wishing to obtain their driver's license and working toward independence.

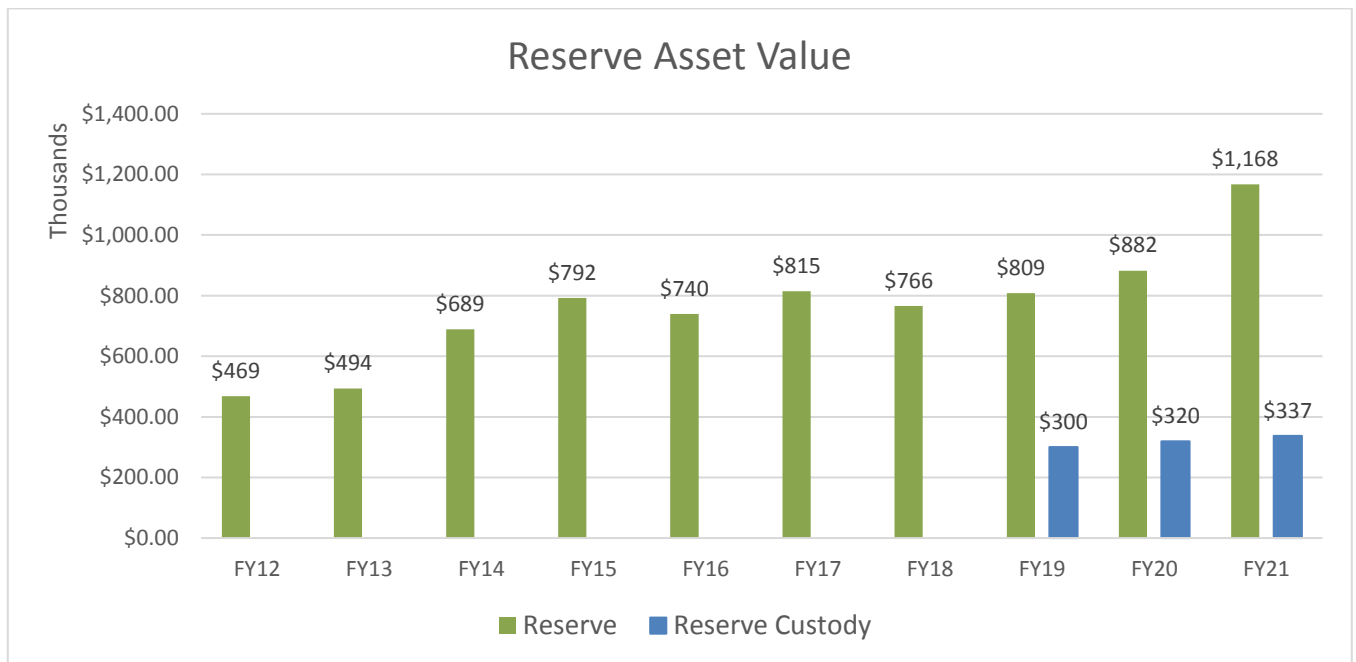


MSNT Operational Budget & Reserves

Each year the MSNT Executive Director is responsible for developing a budget for Board review and approval at its annual meeting. The projected budget estimates income and expenditures for the upcoming fiscal year based on previous budgets, actual expenditures for the previous year, and data analysis related to growth projections. At each quarterly meeting, the Executive Director prepares for the MSNT Board financial reports that present quarterly income and expenses in summary form, compared to the previous year and budget.

MSNT operated well within budget in FY 21. MSNT remains solvent.

The MSNT Board established a reserve account in 2008 to serve as an organizational safety net and promote sustainability for MSNT. In 2018, the Board established an additional reserve account with shorter term investments. These accounts continue to grow through the careful stewardship of the Board. Reserves provide an essential safety net to provide cash flow if the economy shrinks or there is a market correction that impacts investment accounts.



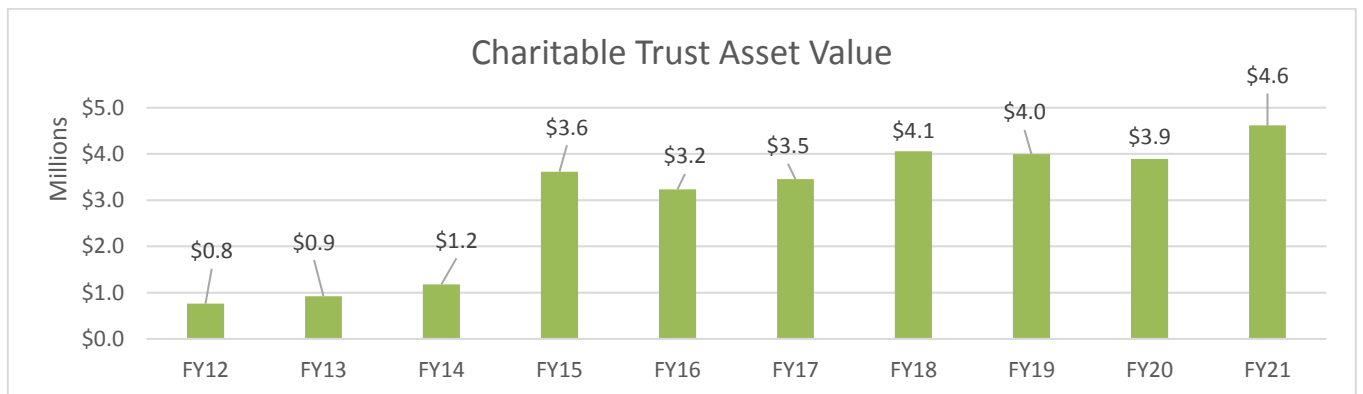


Charitable Trust – The Year in Review

The Charitable Trust provides grants to Missourians with disabilities who are unable to afford supplemental needs not covered by Medicaid or other public benefits. The Charitable Trust has two primary sources of funding.

- The Charitable Trust of the Missouri Family Trust receives 25% of the sub-account balance at termination of the trust as permitted by state and federal statute.
- As a 501(c)(3) organization, MSNT is eligible to accept donations that are added to the Charitable Trust and are tax deductible by the donor.

The Board of Trustees continues to develop strategies to promote sustainability of the program by promoting growth of the Charitable Trust fund through investments and solicitation of donations to the Charitable Trust.



Year	Available for Distribution	# of Grants Awarded	Amount Awarded ⁱ
FY 21	\$244,924	257	\$243,547
FY 20	\$243,620	345	\$326,950
FY 19	\$487,399	505	\$453,163
FY 18	\$325,588	353	\$290,033
FY 17	\$129,564	223	\$176,825
FY 16	\$316,143	340	\$275,349
FY 15	\$220,947	196	\$139,108
FY 14	\$137,859	163	\$117,432
FY 13	\$81,423	86	\$58,693
FY 12	\$80,496	124	\$74,303
FY 11	\$109,605	199	\$114,180

¹Amount available for distribution is from annual report; number of grants and amount awarded reflects all current FY urgent care awards and general awards from last quarter of previous FY plus the first three quarters of the current fiscal year.

In FY 21, MSNT awarded 6 COVID-19 Relief Grants totaling \$120,000, in addition to the \$243,547 in individual grants. The COVID pandemic and subsequent emergency measures implemented to address the health crisis, led to major financial distress for countless individuals and businesses across many industries. Many fixed costs remained due, while the cash flow dwindled or ceased. Select agencies were invited to request a grant from Midwest Special Needs Trust's Charitable Grant Program. Targeted agencies included special needs summer camps, therapeutic riding, art therapy and aquatic therapy. Relief Grants were for the express purpose of aiding agencies providing services to individuals with disabilities with low incomes. Funds from the Relief Grant could be used for any expense required to keep the agency solvent through the global pandemic period as long as the expenses were specifically identified in the application, not covered or available to be covered by other resources and approved in advance through the application process with MSNT.

In FY 21, there were 257 grants totaling \$243,547 awarded to Missourians with disabilities living in poverty – 135 Urgent requests totaling \$148,329, and 122 General requests totaling \$95,218.

Charitable staff work conscientiously to award grants throughout the state to help “fill the gap” for people with disabilities that have unmet needs. We share the following brief stories from FY 21 as examples² of how the Charitable Trust has made a difference:

- 9-year-old Melody has a rare, complex disease affecting her brain and spinal cord. Due to the nature of the disorder, she is unable to perform activities of daily living and must rely solely on care provided by others. Melody, her mother and two younger siblings live in a duplex located in a small town with limited affordable and accessible housing. Relocating to another city would cause the family to forgo much needed natural supports provided by friends and family. As Melody continued to grow, carrying her up and down stairs throughout the day had become a strenuous, unsustainable task for her mother. With a Charitable Grant, the family was able to purchase a portable battery powered stair climbing wheelchair to provide Melody with barrier free access to her home and community.
- Tim is 60 years old and was determined to drive despite having a spinal cord injury. Luckily with today's technology, some basic equipment and certifications it has become easier for individuals who use wheelchairs to operate a vehicle functionally and safely. Tim owned a customized van with modifications giving him the ability to operate his vehicle while seated in his wheelchair. A problem arose when it was discovered that Tim's new electric wheelchair was not compatible with the existing docking base that locks the wheelchair securely in place. MSNT's Charitable Grant Program covered the cost of the new docking system, restoring Tim's independence and getting him safely back on the road.
- 44 year-old Roberta can attest that living with chronic hip and knee pain can make day-to-day activities an ordeal. In fact, there is often not a single aspect of life that chronic pain does not impede. Being able to independently bathe was an elusive goal for Roberta due to the cost of modifications. With a Charitable Grant, Roberta was able to equip her bathroom with

² The names and other details were changed to protect the confidentiality of beneficiaries.

sturdy grab bars and a transfer bench to keep her bathroom floors dry, reducing the risk of a serious fall.

- Frances is a 65 year-old outgoing woman with degenerative arthritis. As her condition progressed, Frances' strength and range of motion declined, requiring the use of an electric wheelchair to stay active and involved in the community. After ten years of use, the wheelchair batteries would no longer charge. Suddenly she was alone and struggling to access her home and the outside world. Without a functioning wheelchair, she could not even retrieve mail from her mailbox. Allocating funds out of her budget to purchase new batteries was simply not feasible. Today, Frances' mobility is restored and the world has opened to her again. With a Charitable Grant from MSNT she was able to purchase two wheelchair batteries and bring independence back into her life.



FY 22 Goals

Although MSNT goals include growth in the number of sub-accounts administered with continued emphasis on quality service, FY 22 goals also reflect key efforts to better serve Life Beneficiaries.

Through the thoughtful and strategic efforts of a prudent Board, MSNT is poised for continued growth. Toward that end, the following goals have been established for the coming year:

- Finalize new Master Trusts with Joinder Agreements
- Responsively update and revise Board Policies
- Increase the number of sub-accounts
- Increase the amounts deposited into sub-accounts
- Promote Inactive Trusts as an estate planning tool
- Recruit Additional Board Members
- Complete a Strategic Planning Process
- Utilize digital marketing software to build a data-driven engagement strategy
- Increase Charitable donations
- Create educational Trust Services videos



Acknowledgements and Appreciation

The success of Midwest Special Needs Trust is the direct result of the vision and persistence of dedicated families who saw a better future for their loved ones with disabilities through the use of Special Needs Trusts. Their commitment to MSNT and their volunteer service as MSNT board members, education and outreach leaders in their communities, have built a solid foundation for MSNT, for which we are most appreciative.

We are humbled by the trust and confidence the Life Beneficiaries and their families have placed in us and we will continually strive to earn their confidence and trust.

We are also filled with gratitude for the many attorneys, human service professionals and Public Administrators who recognize the value of our services and refer clients to MSNT. Statewide, MSNT administers 426 trusts for 47 different Public Administrators. We appreciate their trust and confidence.

We also want to acknowledge the hard work of the staff and the leadership of our Executive Director, Kathy Birkes.

Let this acknowledgment serve as a tribute to the past and a reminder of our ongoing commitment to be diligent in utilizing our expertise to ensure each special needs trust meets its intended need.