NMD United Annual Report 2019

# A Note from the President

Dear Friends of NMD United,

In 2019, NMD United celebrated its fifth year as a qualified non-profit that serves our peers of adults living with neuromuscular disabilities. As a young organization, built entirely by volunteers living with NMD for people with NMD, this year we finally lost our training wheels and started coasting down a windy path full of new adventures.

Our first new adventure began in February when we launched our first grant-funded program, NMD United Unites Texas, and provided contract employment opportunities to over twenty people with neuromuscular disabilities to provide virtual independent living skills (VILS) to our peers in Texas. By the end of this nine-month pilot program, NMD United was so successful that we became the leading organization for other Independent Living organizations to emulate when providing quality peer-to-peer virtual services.

Our second adventure attests to NMD United’s ability to bridge the gap between the individual and a corporation, and create a partnership. We did this for one of our members from Puerto Rico who after Hurricane Maria was dealing with a broken wheelchair that was not able to be replaced or fixed. NMD United took immediate action, made connections, and spearheaded a huge donation of a new Quickie wheelchair within just a few weeks, proving that when our members need help NMD United will go to any length to connect our peers with quality resources.

Our third adventure came about with a variety of social media campaigns, IndependTips, Stop EVV, and Smith’s Showcase. NMD United’s IndependTips increased our social media outreach and audience organically by posting daily tips and tricks of the trade (in accessible formats), which were featured in [New Mobility magazine](https://www.newmobility.com/2019/10/new-mobilitys-biweekly-newsletter-october-2-2019/). Furthermore, we did some intense policy and advocacy work with our Stop EVV campaign as well. Stop EVV provides up-to-date information about the crucial disability rights issue of Electronic Visit Verification, which affects our use of home and and community-based services. Finally, to honor the late and awesome, Greg Smith, a disability rights legend and former board member of NMD United, we created Smith’s Showcase, which will be a place for NMD United to highlight all the talents and stories of our peers.

Our last important adventure is one that we repeat each year with a constant goal to do better the next time around, and that’s with the Alex Landis Empowerment Fund (ALEF). NMD United provided over one hundred independent living ALEF grants to our members in 2019, which just four years ago had a $500 annual budget that has grown to $16,000. Since NMD United does not have paid staff and runs virtually, we can keep our administrative and programming costs very low. This allows us to use 100% of our money raised for the ALEF program for grants that go directly to our community members.

While change never happens overnight, in the non-profit disability world, NMD United is rapidly making our way to being one of the top grassroots, peer-led, organizations in the world that serves adults living with neuromuscular disabilities. We absolutely couldn’t do this without the support of our peers, our volunteer committee members, and those who support our mission as we take on new adventures and head in new directions.

Cheers to future adventures,

Emily Wolinsky

Board President

# Financial Report

## Consolidated Statement of Financial Position: December 31, 2019

### Assets:

Cash

$33,550.75

PayPal Funds

1,508.34

Accounts Receivable

(8.17)

Prepaid Assets

124.48

Total Assets

$35,175.40

### Liabilities and Net Assets:

**Liabilities:**

Total Liabilities

$0

**Net Assets:**

Net Assets without Donor Restrictions

Undesignated

$27,592.66

Net Assets with Donor Restrictions

ALEF Purpose Restricted

$7,582.74

Total Net Assets

$35,175.40

**Total Liabilities and Net Assets**

$35,175.40

## Consolidated Statement of Activities: January 1, 2019 to December 31, 2019

### Revenues

**Contributions**

Without donor restrictions

$15,022.06

With donor restrictions

$43,380.99

Total

$58,403.05

**Net assets released from restrictions**

Without donor restrictions

55,384.33

With donor restrictions

(55,384.33)

Total

-

**Total revenues**

Without donor restrictions

$70,406.39

With donor restrictions

($12,003.34)

Total

$58,403.05

### Expenses

**Program Services**

VILS Contract

36,950.00

Accessible Vehicle Maintenance

4,550.00

Durable Medical Equipment

4215.00

Consumable Medical Supplies

1827.00

Personal Care Assistant Advertising

1129.00

Assistive Technology

36,97.00

Education

680.71

Total program services

$53.053.71

**Supporting Services**

Fundraising

197.70

Management and general

6055.77

Total supporting services

$6,253.47

Total expenses

$59,307.18

### Change in net assets

Without donor restrictions

$11,099.21

With donor restrictions

($12,003.34)

Total

($904.13)

### Net assets at beginning of the year

Without donor restrictions

16,493.45

With donor restrictions

$19,586.08

Total

$35,079.53

### Net assets at end of year

Without donor restrictions

$27,592.66

With donor restrictions

$7,582.74

Total

$35,175.40

\* This only includes applicants who received payments during the 2019 calendar year

# Alex Landis Empowerment Fund (ALEF)

We had another successful year of serving our community with independent living grants to help with disability-related expenses.

**Totals for 2019**

$16,000 spent

102 grants awarded

12 applicants were denied as all funds were exhausted

Accessible Vehicle Maintenance and Repair (VMR):

$4,555 spent

24 applicants served

Assistive Technology (AT):

$4,162 spent

26 applicants served

Personal Attendant Care Advertisements (PCA):

$879 spent

9 applicants served

Durable Medical Equipment (DME):

$4,647 spent

25 applicants served

Consumable Medical Supplies (CMS):

$1,757 spent

18 applicants served

## Giving Tuesday

For Giving Tuesday 2019, all donations made went directly to ALEF to provide independent living grants in 2020. Thanks to our amazing community, we successfully raised over $9,000.

Given these donations, we were also able to increase the Consumable Medical Supplies grant from $100 to $200 for the year 2020.

# Social Media

## Social media growth

Facebook

Up 18%

2190 Likes

Twitter

Up 29%

283 Followers

Instagram

Up 47%

463 Followers

## IndependTips

At the beginning of 2019, we launched our #IndependTips campaign. This volunteer-ran project turned out to be a huge success!

Every day in 2019, our social media shared a "tip" in the form of a meme, video, or photo that could help those in our community increase their independence. Topics related to health improvement, advocacy, personal care attendant management, assistive devices, technology, living independently, vocational supports, parenting with a disability, and more.

Not only did this campaign serve as a way to provide valuable resources and ideas to our community, but it was also an opportunity to collaborate with our followers. Our posts offered a space for our community to discuss ideas and share similar tips that worked for them in their own independent living.

You can explore tips from this campaign by searching the hashtag "independtips" on Facebook, Instagram, and Twitter. Some of our most popular tips include:

# NMD United Unites Texas

In 2019, we were able to launch a new project, NMD United Unites Texas, dedicated to adults living with neuromuscular disabilities who live in Texas. This nine-month pilot project focused on supporting our community through Virtual Independent Living Services (VILS), which connects Texans with neuromuscular disabilities to virtual support, networking, and resources through a secure video and voice chat platform.

We created a space for Texans with any type of neuromuscular disability to join small breakout groups, take classes, advocate for the community, and access networking opportunities — from wherever they live, work, or play. Using online and telephone platforms, VILS and NMD United expanded services to rural communities where disability resources, training, and advocacy opportunities aren’t easily accessible.

Sessions focused on topics that are essential to independent living, including:

**Personal Care Attendant Management:**

Consumer Directed Care vs. Agency Model; PCA Recruiting/Ad Writing; PCA On-Boarding; and PCA Management Techniques

**Assistive Technology Access:**

Adapting a Smart Home; Adaptive Driving

**Socialization:**

Expanding Your Social Circle; Dating, Marriage, and Parenting

**Vocational Development:**

Working and Keeping Benefits; Ways to Work & Job Accommodations (Telework vs. In-Office vs. Hybrid); Vocational Rehab 101; Impairment Related Work Expenses (IRWEs)

**Disability Management:**

Adapting to Ventilation (non-invasive and invasive); Adapting to Disability Progression; and Catheterization Techniques

**Accessing Accessible Transportation:**

Hiring a Driver; and Paratransit vs. Public Transit

This project was supported in part by a grant from The United States Administration on Community Living, Department of Health and Human Services, Washington, D.C. 20201. Texas State Independent Living Council (SILC) distributed VILS project funds to NMD United to use Facebook and Zoom to create trainings, programs, set up one-on-one meetings, and host group conversations virtually.

# Stop EVV

NMD United continues to sponsor Stop EVV, which is a grassroots campaign advocating and fighting to protect the privacy rights of disabled people and their individual providers forced to use Electronic Visit Verification (EVV).

In 2019, Stop EVV focused on expanding outreach and education. They have a support and advocacy Facebook group for 35 states in the U.S. including:

[Alabama](https://www.facebook.com/groups/655712334915603/)

[Arizona](https://www.facebook.com/groups/1349557361870458/)

[Arkansas](https://www.facebook.com/groups/2369701389978124/)

[California](https://www.facebook.com/groups/2362621020662709/)

[Colorado](https://www.facebook.com/groups/179836445984383/)

[Connecticut](https://www.facebook.com/groups/2472422113004624/)

[Florida](https://www.facebook.com/groups/2622083457841957/)

[Georgia](https://www.facebook.com/groups/397033644523513/)

[Hawaii](https://www.facebook.com/groups/448701135854403/)

[Idaho](https://www.facebook.com/groups/2391989221049136/)

[Illinois](https://www.facebook.com/groups/367022817540289/)

[Indiana](https://www.facebook.com/groups/932401037109503/)

[Iowa](https://www.facebook.com/groups/378565716171135/)

[Kansas](https://www.facebook.com/groups/442273846636562/)

[Louisiana](https://www.facebook.com/groups/714743202328150/)

[Maine](https://www.facebook.com/groups/471139063608759/)

[Massachusetts](https://www.facebook.com/groups/512756396192592/)

[Michigan](https://www.facebook.com/groups/375786596702307/)

[Minnesota](https://www.facebook.com/groups/2405601746222588/)

[Missouri](https://www.facebook.com/groups/678704929295647/)

[Nebraska](https://www.facebook.com/groups/407019460002229/)

[New Jersey](https://www.facebook.com/groups/2442666825824610/)

[New York](https://www.facebook.com/groups/NYEVV/)

[North Carolina](https://www.facebook.com/groups/2456126531272949/)

[Ohio](https://www.facebook.com/groups/1807433709344539/)

[Oklahoma](https://www.facebook.com/groups/742444746167408/)

[Oregon](https://www.facebook.com/groups/434743270477336/)

[Pennsylvania](https://www.facebook.com/groups/367305894152059/)

[Rhode Island](https://www.facebook.com/groups/RIStopEVV/)

[Tennessee](https://www.facebook.com/groups/989420364749620/)

[Texas](https://www.facebook.com/groups/928976730797056/)

[Virginia](https://www.facebook.com/groups/2274057822685678/)

[Washington](https://www.facebook.com/groups/WAStopEVV/)

[Wisconsin](https://www.facebook.com/groups/192609708284177/)

[Wyoming](https://www.facebook.com/groups/780015829118808/)

# Smith’s Showcase

In the Spring of 2019, we launched Smith's Showcase to tell stories and promote the talents of adults living with neuromuscular disabilities around the world! This webpage was created to honor the late Greg Smith, who was our friend, a former NMD United board member, and a master self-promoter. So far, we have showcased 12 adults living with neuromuscular disabilities!

Our spotlight features of 2019 were Ing Wong-Ward, Steve Way, and Hannah Soyer. Each of their individual interviews outline their advocacy, work, perspectives, and more.

Previous interviews can be found on [our blog](http://nmdunited.org/blog).

All showcase features can be found on our [Smith's Showcase page.](http://nmdunited.org/smiths-showcase)

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# NMD United Guidestar

Seal of Transparency

2019 Platinum

# NMD United

NMD United, Inc. is a qualified 501(c)(3) tax-exempt organization.

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