



United Cerebral Palsy ("UCP") Affiliate Opportunities and Value Proposition 2021

Vision Statement: Life of inclusion for individuals with disabilities.

Mission Statement: To be the indispensable resource for individuals with cerebral palsy and other disabilities, their families, and their communities.

Mission Statement : The purpose of the corporation shall be to promote the independence, productivity and full citizenship of people with cerebral palsy, intellectual and developmental disabilities, and other conditions, through an affiliate network. (Approved May 26, 2020 by the Members of the Corporation (MOC) in the bylaws revisions.)

Networking

Affiliates are provided opportunities for sharing best practices, -fundraising activities, new program ideas, grant writing and to address common concerns such as personnel issues, governance issues, succession planning, compensation etc. in a safe, non-competitive environment. These opportunities to connect will be encouraged beyond the Executive Director/CEO and into other key Affiliate staff leadership.

- **Engagement Opportunities**

- **Biannual RAC Meetings**

The four regions (RAC's –Regional Administrator Council) are Northeast, South, West and Midwest. The RAC members (Affiliate CEO's/Executive Directors) select RAC Chairs for each of the RACs. Agendas are planned, with input from Affiliates and UCP. The meetings are held twice each year (spring and fall) and generally last 1½ days offering the opportunity for Affiliate sharing and networking time. Since the beginning of COVID-19 the meetings have been virtual and shorter in duration. They are being used as an opportunity for Affiliates to share best practices.

- **Peer-to-Peer Networking**

Connecting Affiliate leadership through RAC Meetings, topical calls and one-on-one connections is one of the biggest values of affiliation with UCP. CEOs have indicated sharing with their peers in a supportive environment is invaluable.

- **Annual Meeting**

Affiliate leaders and volunteers are invited to participate in this two-day meeting, which typically features networking opportunities in smaller groups, presentation of awards such as the Kathy Maul Leadership Award, Chair Award and Legislative Award and the Annual Meeting of the MOC to vote on issues that affect the entire network. We also recognize Affiliate Volunteers and in

2021 will recognize the contribution of DSP's during COVID-19. The Annual Meeting will also include topical speakers that provide valuable perspective of issues relevant to the Affiliate Network and sponsors to help defray costs. In 2020 and 2021, because of COVID the Members of the Corporation meeting was held virtually.

- **Quarterly Virtual Town Hall Call with President & CEO**

This call provides an opportunity for Affiliate Executives to engage with UCP National's President & CEO. In addition, on every call an Affiliate or an invited guest showcases one of their programs or best practices, or resources.

- **Quarterly Topical Calls**

Hosted by one of the four (RAC's), specific topics are presented and/or discussed by experts, inside and outside of the UCP network, in a webinar or teleconference format. Calls are scheduled for one hour.

- **Private Facebook Group (UCP Network)**

This private Facebook group is a place where Affiliates can share events, information, request assistance from peers, celebrate Affiliate successes, and more. You can request to join the group at <https://www.facebook.com/groups/ucpnetwork/>.

- **Volunteer Engagement Calls**

This volunteer-driven group is open to Affiliate volunteers and led by four volunteers representing each of the four RACs. The goal is to have at least one Board Member, from each Affiliate, participate with this group. Participants suggest discussion topics and the calls are led by Affiliate Board Members. The calls are held quarterly and are scheduled for one hour.

- **Affiliate Portal**

The Affiliate Portal is currently being moved to a new online platform where it will be more robust and easier to use. Each Affiliate will have access to the Affiliate pages, Affiliate Executives and their respective team members may be able to find discussion forums, a library (templates, sample policies, documents, recordings), webinars, and other valuable resources created specifically for UCP Affiliates.

- **Listing of Programs and Services Provided by Each Affiliate**

Affiliates frequently are considering starting new services or expanding existing services. UCP has a list of all Affiliates and their current service offerings so that Affiliates can identify where expertise may be available within the network. It is available upon request. Over the years, UCP has also compiled a list of Affiliate staff leadership in several areas of expertise such as Programs, Development, Marketing/Communications, Human Resources and Finance which is available upon request. Note, however, that maintaining a current list is a challenge.

- **Network News**

This monthly e-newsletter provides news about the Affiliate network, highlights significant accomplishments of Affiliates and offers links to news articles of interest to the disability community. Also included in *Network News* is a message from the CEO.

Brand

The UCP brand, logo design, tagline and marks are assets owned and protected by UCP National. Founded in 1949, UCP has a rich legacy, solid reputation and significant brand recognition that opens doors with corporations and policymakers. Affiliates of UCP have provided a wide range of services in their communities under the UCP Brand. Affiliates have served millions of individuals over the years and over 150,000 *individuals with disabilities and their families* are being currently served on an annual basis. Our various websites and social media forums raise awareness of UCP and cross promotion with Affiliates benefits all Affiliates as well. The recognition of the UCP brand has resulted in bequests to UCP that benefit Affiliates.

- **70th Anniversary**

In 2019 UCP celebrated the 70th anniversary of its founding by Leonard Goldenson. UCP has a rich legacy as being one of the nation's oldest nonprofits serving the disability community. Founded in 1949 by parents seeking community inclusion and resources for their children, families came together to advocate, legislate and raise awareness about cerebral palsy. The UCP brand was strengthened through the growth of organizations across the country with the same mission. We reactivated the "we are more than our name" logo for Affiliate use.

- **Bequests**

UCP brand awareness campaigns such as the UCP telethon fundraisers from the 1950's -1980s, including national advocacy efforts, research, services and shared critical information have resulted in donors naming UCP National or a UCP Affiliate in bequests.

UCP National makes every effort to determine the decedent's intention per the testament and will. Over the years, active affiliates have received bequests when clearly determined the funds were intended for that affiliate. More on bequests under **Financial Benefits**.

- **Heckerling Conference**

In January 2020, under the leadership of Ed Matthews, CEO, Adapt Community Network, ten Affiliates came together to provide financial support for sponsorship at the Heckerling Estate Planning Conference in Orlando, Florida. UCP was introduced to the conference by Melanie Schnoll from Morgan Stanley. Over 2,500 attorneys, estate planners, banks and investment firms attended. Many Affiliates benefitted from being provided a list of attendees for their geographic area. UCP will maintain a presence at the conference in 2021 with a Silver Sponsorship which includes a virtual booth and opportunities to contact attendees virtually. UCP Seguin is partnering with UCP National on the 2021 presence.

- **UCP Elsie S. Bellows Fund (Also listed under Financial Benefits)**

Since 1995, children from all over the United States who receive services from UCP Affiliates have benefitted from the Elsie S. Bellows Charitable Fund and her gift of kindness. We would like to tell you a little bit about the woman who funded the Bellows Fund. Although Dr. Bellows is currently deceased, she was a pioneer in her time. Dr. Bellows was a racing chemist. Her job was the detection of drugs in racing horses and greyhounds. Employed by the Florida State Racing Commission, she was the only woman in the 88-member worldwide Association of Official Racing Chemists to head up a laboratory. Hers was the second largest lab in existence with a staff of 12. In her laboratory, she matched her wits and scientific knowledge against unscrupulous trainers. Racing chemistry was a

new field and Dr. Bellows had to do her own research and work out identification patterns for thousands of chemicals that might affect the outcomes of the races. Sly and dishonest trainers in Florida learned to their dismay that they had little chance of coming up with any kind of drug unknown to Dr. Bellows. Dr. Bellows had many interests but found her job as a microchemist intensely interesting. It was because of this honesty and love of animals, people, and nature that Dr. Bellows directed her money go for good causes and the welfare of children and adults with special needs. Each Affiliate receives an allocation of money annually to purchase assistive technology/equipment for individuals with disabilities who lack the financial resources to purchase this technology.

Affiliates receive a Bellows application form, frequently asked questions, guidelines for use of the allocation and an annual report. In 2020, a total of \$654,988 was dispensed to individuals served by Affiliates. Not all Affiliates are using their allocations and we encourage all to make use of the funds.

- **Brand Protection**

UCP ensures that trademarks, domain names, logos, brand design and multiple other UCP-owned brands are monitored and protected. Any violations or brand infringements are addressed in collaboration with UCP National and its trademark/intellectual property law firm based in Washington, D.C., Winterfeldt IP Group, PLLC.

- **Logo Usage/Brand Standards**

The Brand Standards were revised and distributed to all Affiliates in 2018 to ensure that Affiliates are using the logos and trademarks in compliance with Brand Standards and correctly using the UCP trademarks.

- **Life Without Limits**

UCP's *Life Without Limits* quarterly e-newsletter showcases trending stories from UCP's National office, including top headlines, policy updates, Affiliate happenings, and resources. UCP's communications consultant is currently producing the e-newsletter.

- **My Life Without Limits (MLWL) Website (currently offline)**

This primarily online program supports individuals with disabilities from all around the world. It highlights trending news, provides various online resources and promotes ways for individuals to connect with one another. The site is currently offline, but otherwise found at www.MyLifeWithoutLimits.org and will be integrated into the www.ucp.org website in due time.

- **My Child Without Limits (MCWL) Website (the site is currently offline)**

The www.MyChildWithoutLimits.org website is currently offline. Adapt Community Network is developing a new site that will be co-branded with UCP National. There may be a change to the name of the site which provides resources and medical information for parents with children who have developmental or intellectual disabilities. Such changes will be announced to the network.

- **Social Media**

UCP National maintains an active social media presence with more than 45,000 "likes" on Facebook (@unitedcerebralpalsy), nearly 8,200 followers on Twitter (@ucpnational), and nearly 6,200 followers on LinkedIn. (UCP's Instagram account is currently on hiatus.) On its social media pages, UCP shares curated content about the disability community from thought leaders, media outlets

and our Affiliates. We encourage you to follow UCP National on social media and share content with us you would like to cross-promote.

- **Marketing/Communications**

Graphic design support, including, but not limited to:

- Logo manipulation or creation
- Design (social media, events, etc.)
- Opportunities for promotion in UCP's e-newsletters (*Life Without Limits* and *Network News*), social media channels, as well as media support and resources.
- Life Without Limits podcast

Policy and Advocacy

UCP National, both through and alongside our corporate membership with ANCOR, is active on the Hill and with other disability groups to influence legislation that affects people with disabilities and Direct Service Providers alike. This affords UCP a more influential voice as we combine our efforts with other organizations representing people with disabilities.

- **ANCOR membership** - Because of affiliation with UCP, Affiliates are eligible to receive the following benefits from ANCOR:
 - Updates on an array of priority policy issues, along with the means to take action and spread the word through your networks.
 - Representation on a federal level in disability policy discussions and facilitated meetings with Congressional representatives, leaders of agencies, and the sitting White House administration as necessary.
 - Advisements on a state level on disability policy discussions and, in the case of larger states, state coalition representation.
 - Access to policy-themed conference calls that bring together thought leaders and members of the community around specific policy issues.

Apart from the ANCOR partnership, UCP National also collaborates with a number of national advocacy groups to impact legislation important to the disability community.

- **Public Policy Agenda** - In collaboration with the Arc and UCP, AAID, ANCOR, ASA, ASAN, Easterseals, NACDD and TASH, a biannual publication called the Public Policy Agenda summarizes key policy issues and goals for the ("I/DD") community that is distributed to Congress and the White House administration. It is also used to guide most of UCP's policy decisions.
- **Disability Policy Seminar ("DPS")** - UCP National is also a co-sponsor, along with seven other national disability organizations, including The Arc, of the Disability Policy Seminar (DPS), which is held annually in Washington, D.C. each spring. The DPS offers the opportunity for passionate advocates, self-advocates, experts, and professionals in the field to come together and learn about key issues impacting the disability community. After two days of training and learning, attendees head to Capitol Hill for a day of meetings with their Members of Congress. We encourage UCP Affiliate staff, and their clients to attend the DPS and participate in the accompanying Hill Day as that is one of the

most effective ways to help our legislators support the causes that are relevant for the disability community. You can learn more about the DPS at disabilitypolicyseminar.org.

- **Case for Inclusion (CFI)** - The Case for Inclusion (CFI) report has been produced by UCP National since 2006. For the fourth consecutive year, we have partnered with ANCOR and the ANCOR Foundation. The CFI is a leading source for data assessing how well state Medicaid programs serve people with (I/DD) and their families. The most comprehensive report of its kind, the CFI gives lawmakers, advocates and other disability champions a sense of the scope of the challenges faced by professional service providers—a necessary first step to creating a roadmap for how to drive progress in the states to ensure that individuals with I/DD are included, supported and empowered in the community. The most current edition of the CFI report is available at caseforinclusion.org.

Financial Benefits

Over the past four years, changes in management, efficiencies and a greater emphasis on building Affiliate trust have been vital to the existence and future development of UCP National. These efforts focused on strategic steps toward financial sustainability for the organization by creating a new operational model preserving the importance, relevance and viability of its key stakeholders, UCP's national network.

- **Dues Reduction**
October 1, 2017, UCP reduced affiliation dues by 50% for the majority of Affiliates. Affiliates are utilizing those savings to provide services and programs in their communities.
- **ANCOR Membership**
Affiliate dues to UCP includes membership for their Affiliate in ANCOR and affords the opportunity to all Affiliates to benefit from the advocacy and policy work provided through ANCOR. This includes webinars, attendance at conferences, briefings, SOS alerts, and communications provided by ANCOR.
- **Bequests**
In the unlikely event that UCP National is notified of a bequest intended for an affiliate, UCP National reviews the documents, notifies the trustee or the representative of the bequest, and communicates to the UCP affiliate's CEO/Executive Director of the incoming bequest. The affiliate is then responsible for communicating with the trustee or representative of the bequest to complete the distribution.
- **UCP Elsie S. Bellows Charitable Fund**
Each Affiliate has an allocation of money annually to be used for assistive technology for individuals with disabilities. Application forms are a simple one page document and have been shared with all Affiliates. Allocations are based on dues and fall into 4 categories. Affiliates also receive Bellows Guidelines, Frequently Asked Questions and a Memo annually outlining the allocations and categories for the current fiscal year.
- **Melwood Car Donation Program**
UCP works with Melwood, a non-profit agency that provides job training and employment for more than 2,000 individuals with disabilities. Through this partnership, UCP Affiliates receive cash donations for donated vehicles. Melwood and UCP handle the front- and back-end logistics, and there

are no upfront costs to the Affiliate. The Affiliate's responsibility is simply to promote this program as a giving option in their publications. If a donation was made to a specific Affiliate, UCP National redistributes 90% of the proceeds to that Affiliate.

- **Online Donation Program**

UCP's online donation portal gives donors the option to not just donate to the national office, but to any UCP Affiliate as well. This donation option is clearly identified on UCP's website and receives the most traffic for online giving (please note that Affiliates do not have to sign up for this service, since UCP National allows donors to select any Affiliate on the donation page). UCP National's development team is responsible for ensuring that Affiliates receive details about the donations, donor contact, and payment for the previous month. UCP National takes a 1% fee of the total amount an Affiliate receives in online giving for the previous month.

- **Direct Mail Revenue Sharing Program**

Participating affiliates grant UCP National permission to solicit donors we have in our database and who are located in your affiliate territory. UCP National redistributes 100% of the funds collected in your territory back to your affiliate. Participating affiliates receive their funds every quarter with a detailed donor report.

The cost for affiliates to participate is **zero**. UCP National pays for all costs associated with the mailing. We're always looking for opportunities to highlight our affiliates via direct mail, so if you would like to share a success story about a child or adult who received services from your affiliate, we can collaborate and produce a direct-mail appeal detailing the role of your affiliate and the impact on the individual – at no charge to the affiliate.

- **STEPtember Event**

Affiliates can choose to participate in the STEPtember event that is a virtual fundraising event that spans four weeks during the month of September. The event is managed by Cerebral Palsy Alliance and offered to US Affiliates through a long-standing relationship with UCP. **UCP National has no direct involvement in the event.**

- **Information and Referral Services**

Over 1,000 (ranging between 1200-1500) calls for information or referral per quarter are managed via a vendor agreement with UCP of Metro Boston and approximately 60% require referral to an Affiliate. Incoming calls include trying to find an Affiliate in their community or are connected with an Affiliate and asking for other resources for a particular service not offered by the Affiliate. People look to UCP National as a trusted resource for information and are diligent about getting those referrals to UCP Affiliates for service when possible. UCP Affiliates also use UCP National to seek resources for clients if a service is not offered directly by that Affiliate. Given the restructure of UCP National staff, info and referral services are being managed through a contract with UCP of Metro Boston.

Discounts and Vendor Offerings

- **American Red Cross Discounts**

This special discount offers a rate of \$12.00 per person for Cardiopulmonary Resuscitation (CPR) certification. Certifications are for 2 years. Digital refreshers are free during the certification period. These rates include CPR+AED+First Aid per person. Each Affiliate will sign a separate agreement with

the Red Cross, but receive the discounted rate negotiated through UCP. This applies if you are using the Authorized Provider Model (meaning you have your own instructors and train staff in-house, using the Red Cross curriculum).

- **501(c) Agencies Trust**

UCP Affiliates receive a 25% discount when subscribing to the 501(c) Nonprofit HR Hotline. This hotline provides personal attention to all things human resources related. The monthly subscription rate, for unlimited access, is only \$75/month. Additionally, 501(c) Agencies Trust will waive the enrollment fees for Affiliates, which could lead to a savings of \$250 to \$1,000.

Other Opportunities

- **CEO Compensation Support**

Upon an Affiliate request, UCP National can make available the 2020 Guidestar Nonprofit Compensation report provided by a UCP Board of Trustee. The data is pulled from federal 990 forms and the information is based on 2018 data that is presented in several cuts (e.g. by budget, category, location). Upon request to Anita Porco (aporco@ucp.org), we will connect the Affiliate with a volunteer with expertise to assist with guiding the Affiliate in the usage of the data.

- **Home Depot Rebate Program**

UCP National receives from Home Depot a rebate of 5% based on rolled-up expenditures from all Affiliates. The amount is "based on the spend from locations that have an account registered in the ProXtra website for UCP." (https://www.homedepot.com/c/Pro_Xtra)

This program could continue to benefit UCP for many years to come and we very much appreciate those Affiliates that have supported this initiative.

History and Explanation of the Home Depot Rebate Program:

- The Home Depot Rebate Program was introduced to the Affiliates at the RAC meetings in October 2017.
- This rebate program is offered through HomeDepot's ProXtra website, and that would allow UCP National to roll-up all the spending at Home Depot by UCP Affiliates on an annual basis.
- There are three tiers of rebates: \$10,000-\$25,000=1% rebate; \$25,000-\$100,000= 2% rebate; over \$100,000= 5% rebate
- Normally, until an Affiliate spends over \$100,000 annually with Home Depot, the rebate would range from 0% to 2%. By rolling-up all Affiliates expenditures together, the over \$100,000 annual threshold would be achieved.
- Discussions began with Home Depot about the program in March of 2017, however no effort was made to move the program forward until the program could be discussed with as many Affiliates as possible.
- Home Depot would identify any Affiliate that makes purchases at Home Depot using a Home Depot credit card or another credit card to make purchases at Home Depot
- Affiliates would be asked to share their Home depot account number or the credit card account number for the credit card used for purchases at Home Depot

- Affiliates were asked for their support at the October 2017 RAC's allowing UCP National to roll-up Affiliate expenditures at Home Depot to reach the maximum rebate level and to be able to retain the rebate to support UCP National office initiatives. There was great discussion and broad support in all the RAC meetings encouraging UCP to move the rebate program forward.
- Affiliates were advised via email about the Rebate Program on February 21, 2018 and asked to enroll in the program if they qualify.
- There is also a preferred pricing structure available for affiliates doing in store purchases.

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