



United Cerebral Palsy ("UCP") Affiliate Opportunities and Value Proposition 2020

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 (approved May 26, 2020 by the Members of the Corporation ("MOC") in the bylaws revisions): 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.

Networking

Affiliates are provided opportunities for sharing best practices, lessons learned, successes and failures, 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 RAC's. Agendas are planned, with input from Affiliates and UCP National. 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 COVID-19 some of the meetings have been virtual.

- **Peer-to-Peer Networking**

Connecting Affiliate leadership through RAC Meetings, roundtable topics at the Annual Meeting and one-one connections is one of the biggest values of affiliation to UCP. CEO's 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 and as well as a whole entity, presentation of several awards such as the Kathy Maul Leadership Award, as determined by leadership and the Annual Meeting of the MOC to vote on issues that affect the entire UCP network. 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, because of COVID the Members of the Corporation meeting was held virtually.

- **Quarterly Virtual Town Hall Call with UCP 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 showcases one of their programs or best practices.

- **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 Electronic Forum**

The Affiliate Electronic Forum was launched in January 2020 to allow Affiliate staff at all levels to connect with each other around a topic. There are about forty members signed into the forum. The Forum will be embedded into the new Affiliate Portal platform.

- **Affiliate Portal**

The Affiliate Portal is currently being moved to a new platform where it will be more robust and easier to use. Each Affiliate will have access to the online Affiliate pages, where you will be able to find templates, sample policies, documents and other items created specifically for UCP Affiliates.

- **Sharing Success Document**

This resource guide, created in 2011 by Affiliate Executive Directors and CEOs, captures a series of convenings that provide best practices in programs, resource development and social enterprise. An electronic version is available upon request.

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

Affiliates frequently expand or improve upon their 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.

- o **Network News**

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

Brand

The UCP brand is an asset owned and protected by UCP National. Founded in 1949, UCP has a rich legacy, a solid reputation and significant brand recognition that opens doors with corporations and policymakers. The reach of the UCP brand extends to millions of individuals *with disabilities and their families, who are served through the UCP Affiliates*. Our various websites and social media forums raise awareness of the UCP brand and cross promotion with Affiliates benefits all Affiliates as well. The recognition of the UCP brand has resulted in significant bequests to UCP National and to UCP Affiliates.

- **Seventieth 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 disability nonprofits. 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. We continue to utilize the 70th+ logo and relaunched the "we are more than our name" logo for Affiliate use.

- **Bequests**

UCP has been the recipient of multiple bequests each year ranging from several thousand dollars to \$100,000 and has averaged \$289,943.23 annually over the past 5 years. Many of these bequests have come from the UCP brand awareness that resulted from the telethon days. In most cases we are not able to identify a direct connection between the bequeathing individual and UCP. When UCP is notified of a pending bequest, every effort is made to see if it should be redirected to an Affiliate. For Affiliate specific bequests, see notation below under the heading Financial Benefits.

- **Heckerling Conference**

In January 2020, under the leadership of Ed Matthews, CEO of the Adapt Community Network, ten Affiliates came together to provide financial support for sponsorship at the Heckerling Estate Planning Conference in Orlando, Florida. Over 2500 attorneys, estate planners, banks and investment firms attended. There are plans to continue a presence at the conference in 2021. Affiliates are welcome to join their colleagues in supporting the sponsorship and participating in this conference. The conference will be held May 3-6, 2021.

- **UCP Elsie S. Bellows Fund (Also 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 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 the unscrupulous trainer. Racing chemistry was a specific new field, and Dr. Bellows had to do her own research and workout identification patterns for thousands of chemicals that could affect the outcomes of the races, which she found to be energizing. With such brilliance and dedication, the sly and dishonest trainer in Florida learned to his dismay he had little chance of coming up with any kind of drug unknown to Dr. Bellows. Dr. Bellows had many interests, but it was with this passion for the pursuit of higher standards, her love of animals, people, and nature that Dr. Bellows directed her money to go for good causes and welfare of children and adults with special needs.

Each Affiliate receives an allocation of money annually to be used for assistive technology for individuals with disabilities.

Affiliates also receive a Bellows application form, frequently asked questions on Bellows usage, guidelines for Bellows allocations and an annual report on the Bellows distributions. In 2019 a total of \$728,422.03 was expended to individuals served by Affiliates. Not all Affiliates are using their allocations and we encourage all to make use of the available funds.

- **Brand Protection**

UCP National ensures that trademarks, domain names, logos and multiple brands are monitored and violations/infringements addressed through engagement with Winterfeldt IP Group (a trademark firm in DC).

- **Look Into My Eyes Video**

In 2017, Infinitic Media, a division of UCP Seguin of Greater Chicago, produced and released a video called **Look Into My Eyes**, which featured © 2018 Pina Colada Music, and was a huge success thanks to lyrics by Annivar Salgado, Executive Producer, IMPS, music by Janet Alikpala and performance by Eric Brandt. This video was meant to be used by Affiliates to assist in their marketing efforts. The video was revitalized, updated, remixed and released to Affiliates again in February 2018. Affiliates can have the video customized for their Affiliate needs, with their own images at an estimated cost of \$200-\$500.00 through Infinitic Media. The remastered video can be found here: <https://www.youtube.com/watch?v=ncYYViYY3Cw>

- **Logo Generation/Brand Standards**

The logo generation feature is not currently available but with the rebuild of the Affiliate Portal the plan is to make it available again.

Brand Standards were revised and distributed to all Affiliates in 2018 to be certain that Affiliates are using the logos and trademarks in compliance with UCP's Brand Standards.

- **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. It is designed to reach an external audience of donors, friends of UCP etc.

- **My Life Without Limits (MLWL) Website (the site is 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 in due time.

- **UCP Social Media**

UCP National maintains an active following on both Facebook and Twitter, with over 44,000 “likes,” over 43,000-page followers, and over 8,000 followers on Twitter, where we cultivate content from thought leaders, media coverage about disabilities and share our Affiliates’ stories. We encourage you to follow UCP National @unitedcerebralpalsy and share with us any original content you would like us to cross-promote or share.

- **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.

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. This also affords UCP a bigger voice as we combine our efforts with other organizations representing people with disabilities.

- **ANCOR membership** - Because of their affiliation with UCP, Affiliates will receive the following 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 Members of Congress, leaders of Federal Agencies, and the 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 staff provides regular policy representation in DC through a number of organizations.

- **Public Policy Agenda** - Along with a few key players in the Intellectual and Developmental Disability ("IDD") fields, UCP National is a co-producer of the Public Policy Agenda, a bi-annual publication that summarizes key policy issues and goals for the IDD community which is distributed to Members of Congress and the Administration. It is also used to guide most of UCP's policy decisions.
- **Disability Policy Seminar ("DPS")** - UCP National is also a co-sponsor of the ("DPS"), along with seven other national disability organizations, including The Arc, which is held annually in Washington, DC 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 that affect them most. 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 it here: <https://disabilitypolicyseminar.org/about-us/> *Due to COVID-19 pandemic, the organizing partners are aware of the risks for the disability community, and may need to make adjustments to the 2021. Announcements will be made in due time as we evaluate the progression of the virus.*

Case for Inclusion ("CFI") - The Case for Inclusion ("CFI") has been produced regularly by UCP National since 2006, and for the second consecutive year, we have partnered with ANCOR Foundation to produce the report. The CFI has been a leading source for data, assessing how well state Medicaid programs serve people with IDD 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 we face—a necessary first step to creating a roadmap for how to drive progress in the states to ensure that individuals with IDD are included, supported and empowered in their communities. The most current version of the CFI is available here: <https://caseforinclusion.org/about>

Consortium for Citizens with Disabilities ("CCD") - CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. By being a member of CCD, UCP National is able to be on the forefront of the fight to achieve federal legislation and regulations that assure that the millions of children and adults with disabilities are fully integrated into the mainstream of society, thus benefiting the entire UCP network and those we serve.

Financial Benefits

Over the past two years, changes made at UCP National were vital to the sustainability transformation of UCP National, it resulted in a reduction in staff at the national office, through a series of cost cutting measures that either renegotiated or terminated items that were not core to the organization and through the subletting of space in UCP National's current location.

- **Dues Reduction**
Effective October 1, 2017, UCP National reduced affiliation dues by 50% for the majority of its Affiliates. Affiliates can utilize those savings to provide services and programs in their communities.
- **ANCOR Membership**

All UCP Affiliates in good standing with their UCP dues may request membership for their Affiliate in ANCOR. UCP National's partnership with ANCOR, affords the opportunity to all Affiliates to benefit from the advocacy and policy work provided through ANCOR as outlined above.

- **Bequests**

When notification about a bequest is received at UCP National every effort is made to determine if the intention of the bequest is meant for an Affiliate rather than UCP National. Bequests have been re-routed to multiple Affiliates over the years, and have resulted in Affiliates receiving gifts ranging from several thousands of dollars to more than \$20M. Many of these bequests have come from the UCP brand awareness that resulted from the telethon days. It is difficult to predict when one of these bequests may be available to an Affiliate, based on a relationship that was developed years ago and not known to the Affiliate until the passing of the individual.

- **UCP Elsie S. Bellows 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.

- **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 up-front 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 will redistribute 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 those donations made to these Affiliates through the UCP National Donation specific page.. UCP National takes a 1% fee of the total amount an Affiliate receives in online giving through the UCP National specific page.

- **Direct Mail Revenue Sharing Program**

UCP National has a Direct Mail Program where four to five campaigns are produced each year. UCP National does not solicit in Affiliate territory unless given approval to do so by the Affiliate. Affiliates who provide UCP National permission to solicit (via direct mail) in their territory, will receive quarterly redistributions averaging 80% to 100% of the donations raised in their territory at no cost to the Affiliate.

- **STEPtember Event**

Affiliates can choose to participate in the **Stepember** event which 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 UCP Affiliates in the US through a long-standing relationship with UCP National. UCP National has no direct involvement in the event.

- **Information and Referral Services ("I&R")**

Over 1000 (ranging between 1200-1500) calls for information or referral per quarter are managed by UCP National and approximately 40% require referral to an Affiliate. Incoming calls include people 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 that Affiliate. People look to UCP National as a trusted resource for information and we are pleased to pass those referrals to UCP Affiliates for service when possible. UCP Affiliates also utilize the State Resource Guide available on the public UCP website. Given the current structure of UCP National, I&R 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 National. This applies if you are using the Authorized Provider Model (you have your own instructors and train staff in-house, using the Red Cross curriculum).

- **501© 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 - \$1,000.

Other Opportunities

- **CEO Compensation Support**

UCP National has available the 2020 Guidestar Nonprofit Compensation report provided by a UCP Board of Trustee member. The data is pulled from 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 a rolled-up spenditure 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 is an exciting program that could continue to benefit UCP National for many years to come and we very much appreciate those Affiliates that have supported this initiative.

History 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.
- UCP 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 that those that do qualify enroll in the program.

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