



fredla

**FAMILY-RUN EXECUTIVE DIRECTOR
LEADERSHIP ASSOCIATION**



2018

**annual
report**

OCTOBER 1, 2017–SEPTEMBER 30, 2018





FAMILY-RUN EXECUTIVE DIRECTOR
LEADERSHIP ASSOCIATION

Letter from the President

FREDLA reached a five-year milestone this year as it was in September 2013 that 16 executive directors of family-run organizations met in Denver, Colorado to discuss forming an association of executive directors. Since then FREDLA has grown to become a respected source of information, advocacy and technical assistance for local and state family-run organizations. The Board determined that this five-year milestone was a time to reflect on the original concept of FREDLA and plan for the organization's future.

In June 2018, the Board convened in Salt Lake City, Utah to re-examine the mission and consider external factors that could have an impact on FREDLA's direction in the next two years. The result is FREDLA's **2020 Strategic Plan**. Perhaps the most significant outcome of the meeting was a revision to FREDLA's mission. This was done with careful review of the founding documents and principles and with input from member organizations, stakeholders, board members and staff. We are proud to announce FREDLA's new mission statement:



**To build strong, sustainable family-run organizations and
together influence policy and practice to support children and families.**

We believe this mission stays true to FREDLA's original intent while expanding to meet the needs of family-run organizations in a changing and often challenging environment. We extend our deepest thanks to all of our members and partners who have supported FREDLA throughout the years and we look forward to another productive year ahead.

A handwritten signature in black ink, which appears to read "Gail Cormier".

Gail Cormier, President
FREDLA Board of Directors



FAMILY-RUN EXECUTIVE DIRECTOR
LEADERSHIP ASSOCIATION

A New Year — A New Executive Director

Introducing FREDLA's New Executive Director

After an extensive five-month search process, the Family-Run Executive Director Leadership Association's Board of Directors is pleased to announce the selection of **Patricia Hunt** as FREDLA's new Executive Director, filling the role held by Jane Walker for the past 5 years.

Pat is a family member with lived experience and for more than 25 years has been an advocate for children and youth with mental health needs and their families. Pat brings a wealth of personal and professional experience to her new position. Her work with family-run organizations includes developing and directing a family-run organization in Maine; leading policy efforts at the National Federation of Families for Children's Mental Health; and 11 years on Magellan Health's corporate team.



Pat has a history of developing innovative solutions to complex problems and her work spans 42 states. Upon accepting the position Pat stated, "I am eager to work with the heartbeat of the nation's family movement and employ strategic partnerships with national and state leadership to collectively and fully realize the possibilities that accompany times of uncertainty." Pat will begin on Jan. 2, 2019 and can be reached at phunt@fredla.org.

FREDLA's mission is to build strong, sustainable family-run organizations and together influence policy and practice to support children and families. The organization was started in 2013 by 16 executive directors of family-run organizations. FREDLA is a partner with the TA Network at the University of Maryland and provides training and technical assistance to family-run organizations, states and communities to promote family engagement, strengthen family leadership and develop strong family-run organizations.



Learning Community for Family Leaders

At least six times a year FREDLA hosts a Learning Community that attracts family leaders, program directors, System of Care sites and state and local administrators across the country.

- **Supporting Grandparents**
— Jaia Lent, Executive Director, Generations United
- **On the Front Lines: Families and Family-Run Organizations Responding to the Opioid Epidemic**
— Maryland Coalition of Families, National Family Dialogue
- **Confidentiality and SAMHSA Participant Protection Guidelines for Family-Run Organizations**
— Liz Sweet, SAMHSA, and Peggy Nikkel, FREDLA
- **Ethics for Parent Peer Support Providers** — Millie Sweeney, FREDLA
- **Family-Run Organizations Partnering With Juvenile Justice** — Lynsey Heffernan, JDAI State Coordinator; Meri Viano, Associate Director, PPAL; Sarah Murillo, Deputy Chief; Angelica Noriega, Director of Family Engagement and Enrollment, Family Involvement Center
- **What FROs Need to Know About Block Grants** — Tison Thomas, SAMHSA

Topics are always timely and utilize the expertise in the field to share their innovative programs with colleagues.

Learning Community presentations are coordinated through the University of Maryland National Technical Assistance Network for Children's Behavioral Health under contract with the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration.

2018 Board of Directors

Officers

Gail Cormier, President
Executive Director, North Carolina Families United, NC

Paige Pierce, Vice President
CEO, Families Together in New York State, NY

Lisa Conlan, Secretary
Executive Director, Parent Support Network of Rhode Island, RI

Jane Kallal, Treasurer
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Regina Crider, At-large Executive Committee
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Carol Cecil
Executive Director, Kentucky Partnership for Families and Children, Inc., KY

Lori Cerar
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Paul Cornils
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Shannon Crossbear
Co-chair, National Family Dialogue for Youth with Substance Abuse Disorders

Lori Fahey
CEO, The Family Café, Inc., FL

Ruth Fox
Executive Director, Allegheny Family Network, PA

Ann Goldman
Executive Director, Family Based Services Association, NJ

Stephen Graci
Executive Director, Idaho Federation of Families for Children's Mental Health, ID

Michelle Heinen
Executive Director, UPLIFT, WY

Joy Hogge
Executive Director, Families as Allies, MS

Lisa Lambert
Executive Director, Parent/Professional Advocacy League, MA

Janet Pereyra
Executive Director, Federation of Families —Miami-Dade Chapter, FL

Sue Smith
Executive Director, Georgia Parent Support Network, GA

Robin Trush
Advocate

FREDLA on Capitol Hill

FREDLA's Annual Meeting in October 2017 was held in conjunction with The National Council on Behavioral Health's Hill Day. Family leaders joined their state teams to visit their legislators on Capitol Hill.



The following day FREDLA's Annual Meeting opened with greetings from Congressman Joe Kennedy III, District 4 Massachusetts, (at left) who spoke on health care.

Other distinguished speakers included Paolo DelVecchio, Director, Center for Mental Health Services, SAMHSA and Brian Hepburn MD, Executive Director, National Association of State Mental Health Program Directors.



Ethics in Parent Peer Support Workbook: Balancing Your Lived Experience and Professional Roles

Ethics refer to a set of principles, rules, or standards for the conduct of a person or the members of a profession. An ethical dilemma occurs when a person must decide between two or more courses of action. Taking either course of action may have consequences or violate rules, beliefs, convictions, or commonly accepted practice. Deciding upon the best and most appropriate outcome is the core of an ethical dilemma.

Parent peer support providers are frequently faced with ethical dilemmas when working with families, in their workplace and in the community. The Ethics in Parent Peer Support Workbook is a tool to help new and seasoned parent peer support providers practice handling ethical dilemmas.

The Workbook was developed by the Family-Run Executive Director Leadership Association (FREDLA) under a contract with the National



Training and Technical Assistance Center for Child, Youth and Family Mental Health (NTTAC), operated by the National Technical Assistance Network for Children's Behavioral Health (TA Network) at the University of Maryland School of Social Work, funded by the Substance Abuse and Mental Health Services Administration (SAMHSA). FREDLA is a core partner in the TA Network.

More than 20 family members and 14 family-run organizations were involved in the writing and reviewing of materials. FREDLA would like to thank each of the work group members for their time and expertise developing the content and scenarios for the workbook. The Ethics Workbook is available on FREDLA's websites,

http://www.fredla.org/wp-content/uploads/2018/04/FINAL_EthicsParentPeerSupportWorkbook_2018.pdf

FREDLA Honored with Rusty Turner Memorial Award for Excellence



FREDLA was honored to receive the Mississippi Families as Allies **Rusty Turner Memorial Award for Excellence**. The award was presented in November 2017 at the Families as Allies Community Partnership Celebration. The award is named after Rusty Turner, a labor attorney and board member who exemplified Families as Allies vision that all children have the opportunity to reach their potential and be successful. FREDLA was recognized for training materials and online learning communities that have helped families in Mississippi grow into new leadership roles.

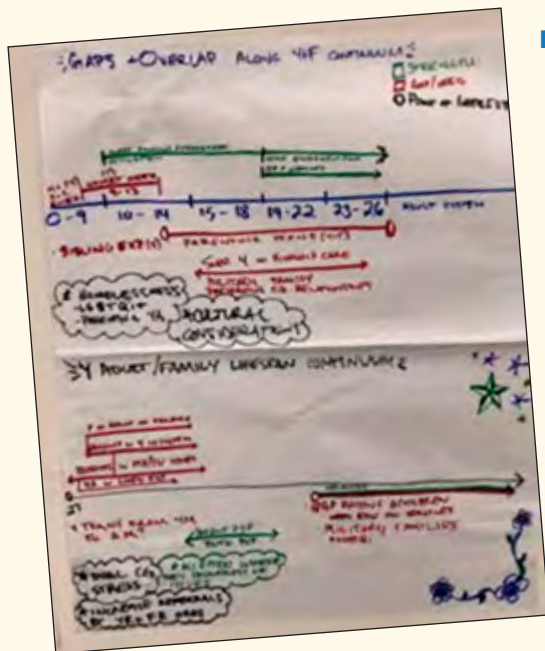
Aligning the Movements

FREDLA/Youth MOVE National Joint Meeting

It involved a scavenger hunt, lots of post-it notes on the wall and a wide range of ages in the room – but it turned into a productive discussion of common ground that moves both youth and family movements forward in the same direction.

In December 2017, FREDLA and Youth MOVE National teams met in Baltimore with support from the National Technical Assistance Center for Children's Behavioral Health operated by the University of Maryland School of Social Work under a contract with SAMHSA.

The one-day meeting led to several key areas of agreement including:



- Alignment does not mean being in a lock step
- We can and should develop shared strategies, as well as model this for the field
- We need cohesion and to prevent working at cross purposes
- We each need space to acknowledge differences
- We shared and agreed upon language and definitions
- We have mutual respect and have each other's backs

Youth MOVE National and FREDLA work in partnership throughout the year on many initiatives such as evaluation and training. It is a partnership that crosses generations and mutually benefits all ages and movements.



Children's Mental Health Awareness 2018 Celebrating Family Leaders throughout the Country

More than 30 years ago, family members stepped forward to start a movement that would change the course for families caring for a child, youth or young adult with behavioral health needs. To celebrate Children's Mental Health Awareness Day 2018, FREDLA put a spotlight on 20 family leaders across the country who have worked in their states, communities and tribes. Some leaders were involved in starting the family movement while others are new to the family movement. Their stories are inspirational and, while each family leader's story is unique, the common thread is their children's mental health needs and a desire to change the system so other families might have an easier time getting help for their children.

On Children's Mental Health Awareness Day - and every day - FREDLA thanks all of the family leaders across the country for the work they do to support families and improve systems of care for our children.





In January 2018, FREDLA embarked upon a multi-pronged process with the National Training and Technical Assistance Center for Children’s Behavioral Health to develop guidelines for the field on family involvement with youth transitioning to adulthood.

As we know, transition from adolescence to a young adult is a normal stage of development that involves physical, cognitive, emotional, and sexual development along with addressing issues of employment, housing, education, and social relationships. It is challenging under the best of circumstances. The presence of a mental health conditions compounds all of the normal, expected milestones for young adults. This is what makes the issue of family involvement so important and often so absent from services for youth transitioning to adulthood.

FREDLA developed multiple strategies to solicit input as we took on the major challenge of developing guidance for the field on family involvement for youth transitioning to adulthood.

The first step was to convene researchers and TA Centers to review the research and identify what works and what doesn’t. In March 2018 FREDLA hosted an Expert Convening with 6 national TA centers (BRSS TACS, PRA, CARS, Portland State, U Mass & U MD) along with four national organizations (NAMI, FFFCMH, Youth MOVE and FREDLA) and four statewide family networks (PPAL, North Carolina Families United, Family Involvement Center in Arizona and Utah Families as Allies) to explore the issue of family involvement after a youth turns 18 years old. Participants concluded there is a limited number of research studies and almost no best practices around family

engagement for youth transitioning to adulthood.

Step two was to solicit direct input from families on their experiences and recommendations. Over the summer of 2018, FREDLA partnered with ten family-run organizations to conduct virtual discussion groups with 65 family members of young adults between the ages of 18 and 25.

Step three was to use the same approach to solicit input from young adults on their experiences and recommendations. In the fall of 2018, FREDLA held five virtual discussion groups with more than 20 young adults between the ages of 18 and 25 from Miami Youth MOVE, On Our Own of Maryland, North Carolina Families United, the Youth MOVE National Best Practice Committee, and the Youth MOVE Chapter in Kentucky. Information is currently being analyzed, and we anticipate guidelines to be released in the coming year.

Antipsychotic Medications for Children

Family Experiences with the Use and Monitoring of Antipsychotic Medications for Children

Growing concern about the use and monitoring of antipsychotic medications for children and adolescents led SAMHSA to convene an expert panel to look at Implementation of Best Practices in Antipsychotic Prescribing for Children and Adolescents. The panel's charge was to develop a SAMHSA Guidance Document for Effective Implementation of Psychotropic Medication Safety Guidelines in Children and Adolescents. As a member of the expert panel, FREDLA ensured that the panel's efforts



included the perspective of families. FREDLA conducted a series of four focus groups with families to provide family input into the expert panel deliberations.

Families reported serious concerns about the side effects of antipsychotic medications, particularly weight gain, breast enlargement in boys, and sleep or drowsiness issues. When their children experienced these side effects, they

reported that doctors often prescribed additional medications to counter the side effects. This resulted in a vicious cycle of multiple medications and frequent changes in medications to the point that families were uncertain as to which medication was causing or treating each condition.

Families also spoke at length about stigma resulting from side effects. The stigma

associated with the side effects and the challenges they cause are often greater than the child's mental health concerns. The children who experienced severe side effects often refused to take the medication. Families reported that their children were bullied in school and experienced social isolation because of weight gain and enlarged breasts.

Results of the focus groups were shared at the Expert Panel Convening at SAMHSA in May 2018. The full report is available on FREDLA's website

<http://www.fredla.org/wp-content/uploads/2018/10/FREDLA-FOCUS-GROUP-ON-ANTIPSYCHOTIC-MEDICATIONS-REPORT-Final-5-8-18.pdf>



Early Childhood Family Network

Gather Family Members in a Room and See What Happens!

It happens every time! Gather a group of family members in one place and they instinctively begin to organize and want to reach out to support other families. That is what happened in February 2018, when 55 family members connected to Project LAUNCH Early Childhood grantees gathered at SAMHSA for a Family Leadership Summit. FREDLA facilitated a portion of the Summit and has been privileged to continue working with this emerging Early Childhood Family Network. Since February, family members across the country have been meeting virtually to turn their vision into a reality.

Parent Peer Support Practice Model

The PPS Practice Model was launched in 2017, offering curriculum for parent peer support providers and their supervisors, a Train the Trainer, and coaching for trainers in the “how to” phases of parent peer support: **Connect, Discover, Support, Empower, Prepare and Take Care.**

As of the end of this fiscal year, more than 100 parent peer support providers and 40

supervisors have completed the training, and 13 trainers have completed the credentialing process to offer the training in their state.

Per training evaluations, all participants reported that their knowledge increased in targeted areas, that the training enhanced their skills and knowledge, and that they would recommend the curricula to others.

Now Is The Time TA Center

For the past two years FREDLA has been a core partner with the Center for Applied Research Solutions (CARS) in the Now Is The Time Training and Technical Assistance Center; the TA Center for the Healthy Transitions, Project Aware, and ReCAST grantees.

FREDLA’s role was to provide expertise in family engagement, parent peer support, family-run organizations, and lived experience with child-serving systems to grantees as well as TA Center staff.

During the past year, FREDLA participated in the development of several distance learning opportunities and products on topics such as social marketing, civil commitment, and collaboration with non-traditional stakeholders such as family-run organizations.

In September 2018 SAMHSA eliminated funding for this Center. FREDLA is grateful to CARS for their leadership of the TA Center, and we look forward to continued collaborations with the core partners of the TA Center beyond 2018!



What A Week!

2018 Training Institutes

Family Leaders, family-run organizations and FREDLA were well represented during the University of Maryland's Summer Training Institutes in July 2018:

- Gail Avent, Executive Director of Total Family Care Coalition in Washington, D.C. provided a plenary session to kick off the Training Institutes
- Regina Crider, Executive Director of Youth & Family Peer Support Alliance in Illinois, lit-up the room with an Ignite Talk
- FREDLA partnered with family leaders, Youth MOVE National, and more to offer a pre- Institute, an Institute, six workshops, a poster session, and a learning community on a variety of topics related to family-driven care, leadership and engagement.

Leading from the Heart

Leadership Traits That Are Unique to Family Leaders

During 2018 Summer Training Institutes, FREDLA presented a half-day session on leadership for family

leaders. The session called, *Leading from the Heart*, was part of the two-day pre-Institute on The Art and Practice of Adaptive Leadership for Systems Change led by Ellen Kagen and Shannon Crossbear.

FREDLA's session focused on factors unique to family leaders such as:

- Lived experience is the major qualification
- Passion for our children drives our work
- Learning is mostly on-the-job training in business/management/governance skills rather than formal training



- We have many roles and a unique relationship with the system: sometimes as a provider in system, or an advocate outside of system, and often a user of system services for our children
- We use our influence as unauthorized leaders.

Twenty family leaders participated in the leadership session and all felt it was an opportunity to share in a safe place, get support from others and grow from the experience.

Family Research Partnership

We instinctively know that family support is effective and that family-run organizations have good outcomes, but we need research to prove it. That is why FREDLA has had an ongoing commitment to fostering research. FREDLA continued to partner with family-run organizations, researchers, universities and systems to study family support and the impact of family-run organizations to inform both our work and the field. This year FREDLA has been involved in a number of research and data gathering initiatives:

- Completion of the final tier of the PCORI Pipeline to Proposal grant and continued facilitation of the national Family Research Partnership
- Submission of an R34 family navigator research proposal to NIMH and a Letter of Intent for a PCORI Capacity Building Engagement grant
- Facilitation of discussion groups with both youth and families around the topic of family involvement in transition age services and with families regarding their experiences with antipsychotic medications and prescribing practices; this information is shared through dissemination of reports and guidance to the field

“Research is creating new knowledge.”

--Neal Armstrong

- Analysis and use of data on youth and family engagement in systems of care via our Westat contract and in partnership with Youth MOVE National.

For information about the Family Research Partnership or FREDLA’s research initiatives, contact info@fredla.org.

SOAR Expert Panel & SOAR Child Curriculum

FREDLA was pleased to participate on the SOAR (SSI/SSDI Outreach, Access and Recovery) Expert Panel and in the development of the SOAR Child Curriculum through the SAMHSA SOAR TA Center operated by PRA, Inc.

FREDLA will continue as a member of the Expert Panel and workgroup on Integrating SOAR and Peers in the next fiscal year.



In FY 18, FREDLA:

- Provided 329 hours of technical assistance for 28 states
- Visited 14 states
- Attended 13 national conferences

Thanks to Our Member Family-Run Organizations

All of FREDLA's Learning Community calls, publications and presentations tap into the expertise of our members and those in the field. Thank you to all of the family-run organizations for your support in the past year!

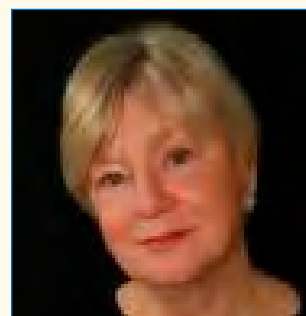
- Alaska Youth and Family Network, AK
- Allegheny Family Network, PA
- Association for Children's Mental Health, MI
- Champions for Children, DE
- FACT Missouri, MO
- Families ASAP, NM
- Families Together in New York State, NY
- Family Based Services Association of New Jersey, NJ
- Family Involvement Center, AZ
- Federation of Families, Miami-Dade Chapter, FL
- Formed Families Forward, VA
- Georgia Parent Support Network, GA
- Hunterson Somerset Warren Family Support Organization, NJ
- Idaho Federation of Families, ID
- Illinois Youth and Family Peer Support Alliance, IL
- Kentucky Partnership for Families and Children, KY
- Maryland Coalition for Families, MD
- Mississippi Families As Allies, MS
- Nevada PEP, NV
- North Carolina Families United, NC
- Ocean County Family Support, NJ
- Oregon Family Support Network, OR
- Parent Professional Advocacy League, MA
- Parent Support Network of Rhode Island, RI
- South Carolina Federation of Families, SC
- The Family Café, FL
- Total Family Care Coalition, DC
- Uplift, WY
- Vermont Federation of Families, VT
- Barbara Granger, TX
- Kristen Grebey, PA
- Fran Purdy, OR



In Remembrance: Sybil Goldman

Sybil Goldman was a visionary and pioneer in the Child and Adolescent Services System (CASSP) program in 1985 in her role as Director of the GUCCHD's National Technical Assistance Center for Children's Mental Health.

Sybil's quiet and reserved way belied her strength to change systems. At the time the family movement was just emerging, Sybil was unwavering in her commitment to family voice. She found ways to support the newly established National Federation of Families and at Georgetown's Training Institutes always made sure the voices of families were present. In her later role as Senior Advisor for Children at SAMHSA, she championed the voices of families within the agency.



Thank You!

So many people and partner organizations have contributed to FREDLA's accomplishments in the past year. We extend our sincere thanks to all of them!

SAMHSA

Paolo del Vecchio, Gary Blau, Elizabeth Sweet, Lisa Rubenstein, Tison Thomas, Yanique Edmond, Jen Oppenheim, Justine Larson, Stacey Lee, Larke Huang

University of Maryland TA Network

Michelle Zabel, Marlene Matarese, Denise Sulzbach, Emily Goldman, Sheila Pires, Kathy Lazear, Beth Stroul, Dayana Simons, Shannon Robshaw, Becky Lieman, Zalika Woods, Gary Wolnitzek, Angelina White, Virginia Mutuura, Tiara Brown, Melissa Schober, Suzanne Fields, Christopher Bellonci

Center for Applied Research Solutions (CARS)

Kerrilyn Scott-Nakai, Miranda March, Christina Borbely, Amy Springmeyer, Jacquie Vatter, Kari DeCelle, Renay Bradley, Amanda Lipp

Change Matrix,

Elizabeth Waetzig, Rachele Espiritu, Suganya Sockalingam, Shannon Crossbear

Children's Hospital of Colorado

Bruno Anthony, Mimi Troxel

NAMI National

Teri Brister

National Assoc. of State Mental Health Program Directors (NASMHPD)

Brian Hepburn, David Miller, A.J. Walker

National Federation of Families for Children's Mental Health

Lynda Gargan

BRSS TACS Center for Social Innovation

Livia Davis, Valerie Gold, Elaine Slaton

Youth MOVE National

Johanna Bergen, Brie Masselli, Alice Topaloff, Kristen Thorpe, Michael Collado, Lydia Proulx, Madeline Zielinski, David McClung

Early Childhood Family Network

Tish MacInnis, Caroline Austin, David Armstrong, Jerry Haruna, Mary Schmidt, Jill Miller, Princess Mack, Vadonna Williams

Portland State University

Janet Walker, Nancy Koroloff, Barbara Friesen, Emily Taylor

Policy Research Associates

Abigail Kirkman, Kristin Lupfer, Matt Canuteson

University of Massachusetts

Kathryn Sabella

University of Washington

Eric Bruns, Spencer W. Hensley, Ryan M. Parigoris

Westat

Abram Rosenblatt, Chandria Jones, Allen Daniels, Paul Weinfurter

PARTNERS

New York University: Kimberly Hoagwood, Anne Kuppinger

University of Maryland, SSW: Geetha Gopalan

Inquisithealth: Ashwin Patel

Vanguard: Stephanie Duke, Shannon Walsh, Ryan Parks, Barbara Huff

HyperMedia: Andy Balto, Cyndi Schwartz

Quinter Design: Robyn Quinter, John Quinter

Generations United: Jaia Lent

Consultant: Ryan LaLonde

Consultants: Pat Hunt, Josephine Hawke

US Department of Health and Human Services Children and Youth Policy Division:

Cheri Hoffman, Director

Financial Position

*Audit of FY 17 finances conducted
by the firm of Weyrich, Cronin & Sorra
Certified Public Accountants & Business Consultants*

FAMILY-RUN EXECUTIVE DIRECTOR LEADERSHIP ASSOCIATION, INC.

Statements of Financial Position September 30, 2017 and 2016

ASSETS

	2017	2016
CURRENT ASSETS:		
Cash	\$ 90,238	\$ 20,209
Contracts receivable	64,204	121,543
Prepaid expenses	2,500	- 0 -
TOTAL CURRENT ASSETS	156,942	141,752
PROPERTY AND EQUIPMENT:		
Computer equipment	1,440	1,440
Website	43,520	43,520
	44,960	44,960
Less: accumulated depreciation	(29,414)	(14,707)
PROPERTY AND EQUIPMENT - NET	15,546	30,253
TOTAL ASSETS	\$ 172,488	\$ 172,005

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES:		
Accounts payable and accrued expenses	\$ 18,568	\$ 37,610
Deferred revenue	11,500	9,948
TOTAL CURRENT LIABILITIES	30,068	47,558
NET ASSETS:		
Unrestricted	142,420	124,447
TOTAL LIABILITIES AND NET ASSETS	\$ 172,488	\$ 172,005