



Lifelong Advocates for Marylanders with Developmental Disabilities

## **Annual Meeting and Luncheon**

November 3, 2018  
Hellas Restaurant

- 10:00 Welcome** Mark L. Wagner, DMD, By Their Side Board President
- 10:05 By Their Side Annual Report**
- 10:35 Moving Forward with Person Centered Services in Maryland**  
What is the vision of person centered services, and how can families advocate for their relative?  
*Joanna Pierson, Ph.D., is Executive Director of The Arc Frederick County. She is a Fellow and Past President of the American Association on Intellectual and Developmental Disabilities, and teaches Social Work at the University of Maryland.*
- 11:35 Break**
- 11:45 Buffet Luncheon**
- Martin Lampe Leadership Award Presentation**
- 1:00 The Coach Approach to Support**  
The Coach Approach develops personal independence and self-esteem for people with intellectual/developmental disabilities. Through demonstration and participation, staff and families alike can coach!  
*Beth Greenland, PAA, is coach and founder of Coach Approach Partners  
Monica McCall, Ph.D., is Executive Director of Creative Options. Together they adapted the Coach Approach to support for people with IDD.*
- 2:00 Adjourn**

# *Special Thanks*

## **CONTRIBUTORS TO TODAY'S ANNUAL MEETING**

Ms. Ann Brady  
Ms. Susan Buehl  
Mrs. Alise Burriss  
Mr. and Mrs. David Cacciaglia  
Mr. Dennis Chekan  
Ms. Joan Chevalier  
Mrs. Janet Cielsielski  
Mr. and Mrs. Edward Dahlka  
Mr. and Mrs. Robert Dunker, Jr.  
Ms. Susan Eicher  
Ms. Allison Fedarko  
Mrs. Cheryl Geske  
Mr. and Mrs. Joseph Knapp  
Mrs. Barbara Lampe  
Dr. and Mrs. Phil Levinson  
Mr. and Mrs. Tony Luciano  
Ms. Beatrice Rodgers  
Ms. Ilene Solomon  
Mrs. Carol Stover



## **BOARD OF DIRECTORS FY 2019**

**President:** Mark L. Wagner, DMD  
**Vice President:** Mary E. Scott, M.Ed.  
**Treasurer:** Jeffrey A. Dahlka, Sr., MBA  
**Secretary:** Paula Mattson-Sarli, Esq.  
**Directors:** Joan Chevalier, Ph.D.  
Janis Ellis, M.Ed.  
George Failla, Jr., Esq.  
Barry Gordon, Ph.D, M.D.  
Phil Levinson, DDS  
Ken Moore  
Judy Volkman  
**Director Emerita:** Joan Kolobielski, MA



## ANNUAL REPORT TO SPONSORS

November 3, 2018

The Board of Directors presents the following report on the status of By Their Side.

### Membership

As of October 15, 2018, 255 people are enrolled in By Their Side, with five additional people in process of enrolling. Of these, 86 members have an Advocate who provides lifelong advocacy services in the form of an annual assessment visit, action to address concerns, and update reports to siblings or Trustees. Three people began this service in the past year. 169 members have sponsors who continue to provide advocacy, and their services will begin in the future. *Sponsors are reminded to establish a plan of notification to expedite timely initiation services.* Seven people receiving advocacy services passed away this year. Advocates also serve 49 people through Annual Advocacy Plans ranging from quarterly to monthly visits, or assistance to help families resolve specific advocacy concerns. Of these, 14 receive lifelong advocacy services with Trustees who have arranged more frequent monitoring visits, 32 have living sponsors, and 3 are not members.

### Advocacy Services

Experienced Advocates assist By Their Side members as needed. For example, Advocates have:

**Addressed health and safety.** Carol's Advocate requested a nutritional evaluation to guide her diet and snacks. More nutritious snacks are helping to keep Carol's blood sugar and mood steady during the day.

**Arranged emergency services.** When medical professionals reported Mary was verbally abused by her caregiver, her agency determined the claim was not substantiated. As requested by Mary's sister, their Advocate set into motion plans for respite while family interviewed other residential agencies.

**Helped pursue individual interests.** Mark's legs are very flexible but he is discouraged from moving them up and onto his wheelchair. A Physical Therapy evaluation has been requested to assess opportunities for activity out of his chair. Susan loves music and is being helped to obtain an adaptive radio switch so she can select music based on her mood. These were Enrichment Assessment recommendations.

**Facilitated use of Special Needs Trusts.** Susan's Advocate arranged an Occupational Therapy evaluation that identified new activity options based on her sensory preferences. Other examples include purchase of a travel wheelchair to increase participation in outings, bedroom furniture, vacations, and art studio fees.

**Assisted siblings near and far - as local eyes and ears, sounding board, and partner in advocacy.** Ken's brother didn't understand why service funding was being threatened until his Advocate helped review assets and explained the need to spend funds in excess of \$2000 or transfer to an ABLE account or first party Trust so Medical Assistance and Waiver enrollment would be restored.

## **Financial**

As of October 30, 2018, By Their Side's assets are \$1,263,343. Investments are managed by Harbor Investment Advisory. The Finance Committee follows the Board's conservative investment policy to assure future services for our members. Operating funds are drawn from Annual Advocacy Plan and investment income, and undesignated donations. This year By Their Side received a \$10,000 bequest from the estate of Mrs. Felicia Haffmans, and a \$64,382 bequest from the Edwin W. Grayson Trust. By Their Side's annual audit of financial records for fiscal year ending June 30, 2018 is underway. Naden/Lean, LLC's 2017 audit reported the financial statements "present fairly, in all material respects, the financial position of By Their Side, Inc as of June 30, 2016 and 2017, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States."

The membership fee for lifelong advocacy is \$3500 for sponsors under 70 and \$4000 for sponsors age 70 and above. Fees were adjusted based on the March 2018 Actuarial Study which applies a conservative projection of investment gain. The fee for Advocacy plan services remains \$85/hour for members and \$100/hour for non-members.

As requested by families, the Board approved prefunding of Annual Advocacy Plan Services. This assures additional visits (beyond the annual assessment visit) begin at the frequency desired by parents while Trustees become familiar with By Their Side's role, enables relatives to gift advocacy services pre-tax within the limits advised by their accountant, and enables parents not establishing a Special Needs Trust to arrange more frequent assessment visits in the future, after they are gone.

## **Personnel**

Employees include Kathy Vecchioni, Executive Director (20 hours/week) and Personal Advocate; Beverly Rill, Financial Coordinator (16 hours/month) and Personal Advocate; and Whitney York, Administrative Assistant (8 hours/week.) Thirteen experienced contractual Advocates also provide advocacy services—Nancy Berger, Kari Borgealt, Ann Brady, Susan Buehl, Ron Christian, Karen Gipson, Paul Mysak, Cathy Raggio, Beatrice Rodgers, Joan Rumenap, T. Gail Singletary, Portia Willis, and Tracy Wright (Enrichment Consultant)—for a total of 15 Personal Advocates working from home offices throughout Maryland. Advocate qualifications are available at [www.bytheirside.org](http://www.bytheirside.org).

## **Governance**

By Their Side is governed by a volunteer Board of Directors comprised of seven parents, two siblings, one self-advocate, and two community members. Directors serving in Fiscal Year 2019 include: Mark L. Wagner, DMD, President; Mary Scott M.Ed., Vice President; Jeffrey Dahlka, Sr. MBA, Treasurer; Paula Mattson-Sarli, Esq. Secretary; Joan Chevalier, Ph.D.; Janis Ellis M.Ed.; George Failla, Jr, Esq., Barry Gordon, Ph.D, M.D.; Philip Levinson, DDS; Ken Moore; Judy Volkman; Joan Kolobielski, Director Emerita.

Respectfully submitted,



Mark L. Wagner, DMD  
President

## BY THEIR SIDE

### PAST TRUSTEES AND BOARD MEMBERS

(1963-71)	Hon. Gilbert Gude	(1988-94)	Randy van Dolson, Esq.
(1963-71)	Joseph H. Hahn, Jr.	(1988-95)	Bill Eicher
(1963)	Martha Quinotte	(1989-91)	Florence Bailey
(1963-71)	Rev. Raymond Purnell	(1990-92)	Corky Andrews
(1963-81)	Marvin Steinberg	(1992-93)	James Turner
(1963-67)	Frederick Storm	(1992)	Kathy Berge
(1963-81)	Milton Feher	(1992-94)	Raymond Starr
(1963-74)	Hon. J. Harold Grady	(1993-94)	Angela Eaves, Esq.
(1963)	George M. Radcliffe	(1995-97)	Bea Kolchin
(1967-80)	Barbara Marlowe	(1995-00)	Frances Macsherry
(1967-74)	Hon. Paul E. Alpert	(1996-99)	Kim Knapp
(1967)	Rev. Robert Bavender	(1997)	Minna Culiner
(1971)	Francis J. Meagher	(1997-00)	James Murtha
(1971)	Rev. Kenneth Nowack	(1999)	Lynn Albizo, Esq.
(1974)	Lambros Callimahos	(1992-00)	Harvey W. Yurow
(1974-79)	Rev. Donald Lawson	(2000)	Donna Rae Smith
(1974)	Hon. Martin Kircher	(1997-00)	Christine M. Rykiel
(1978)	Greg Silverberg	(1993-02)	Dorothy Baranauskas
(1978-94)	Charles L. Mobley, Jr.	(2001-03)	Patty Wolfe Buckner
(1979-82)	Al Brown	(1984-03)	Shirley Carson
(1979-84)	Carl Storm	(1994-04)	Louise Michaux Gonzales, Esq.
(1980-84)	Anne Buchanan	(1995-05)	James Kushel
(1980-85)	Dick Depkin	(2001-07)	William D. Ward
(1981-84)	Jim Chapman	(2003-09)	Dean E. Hoffman
(1981-86)	Fred Ederer	(2004-10)	Victoria Grace, Esq.
(1981-87)	Alyce Reiter	(2007-10)	Jonathan Acton, Esq.
(1984)	William McDonald	(2008-11)	Patricia Davis
(1984-87)	Cal Bond, Esq.	(1998-13)	Marcia Carow
(1985)	Conrad Varner	(2001-13)	Colleen Sinclair-Prosser, Esq.
(1985-86)	Raquel Schuster Herr	(2001-13)	Kim Knapp
(1985-87)	Dorothy Lattner	(2008-14)	Margaret Ulle
(1987-96)	Barbara Soth	(2014)	Shannon Hammond, Esq.
		(2006-15)	Martin Lampe
		(2010-17)	Craig Hebert
		(2015-17)	Tracy Wright

## BY THEIR SIDE TIMELINE

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- 1963- First meeting establishing Arc Maryland Retardate Trust. Trust Corpus account established.
- 1965- First application approved. Membership fee set at \$500. Members visited by Trustees or volunteers.
- 1974- Name changed to "Maryland Trust for the Retarded". 15 members.
- 1979- Name changed to "Maryland Trust for Retarded Citizens (MTRC)".  
Individual monitoring services established. Membership fee increased to \$1,000.
- 1981- Set target of 200 members to make MTRC solvent. Policies and procedures established.  
Luanne Frebertshauser became first social worker to provide professional advocacy services.
- 1982- First sponsors meeting held. Membership fee increased to \$1,200.
- 1984- First MTRC Newsletter was distributed.
- 1985- Goal of 200 members was reached. First scholarship money of \$1,200 was received.  
Volunteer visitor project. 213 inactive, 5 active members.
- 1986- Donated computer received from the McNulty Foundation. Membership fee increased to \$1,500.
- 1989- Board committees formed. Membership fee increased to \$2,000.
- 1990- Housed with Arc Maryland, when it moved to Annapolis, MTRC moved to Arc Carroll.
- 1992- Actuarial study conducted on sustainability of MTRC services.
- 1993- Based on actuarial study, member service changed to 1 assessment visit with follow up each year.  
Additional monitoring visits available as fee-for-service. 39 members withdrew with refund of membership fee. Members whose sponsors were gone continue to receive original service.
- 1994- Advocacy service plans were defined. Volunteers received training.
- 1996- Education Committee formed with focus on assisting families with transition planning.
- 1997- Membership directory developed to help families and siblings meet and network.
- 1998- MTRC goes online with website and email.
- 2000- Long range planning. Investment Fund moved to BB&T. 38 Active, 248 Inactive Members.
- 2001- Family information updated; families surveyed about future plan. 42 Active, 244 Inactive Members.
- 2002- Investment Fund moved to Alex Brown. 44 Active, 241 Inactive Members.
- 2004- MTRC Incorporated and approved as a 501(c)(3) charitable organization.  
Grant funded printing and distribution of educational material. 43 Active, 240 Inactive Members.
- 2006- 5 professional case managers serve 53 Active Members. 229 Inactive members.
- 2007- Case Managers re-named "Personal Advocates". 60 Active, 222 Inactive Members.
- 2008- Board consults with Incite Creative, LLC, approved name change "By Their Side, Inc." with tagline, "Lifelong Advocates for Marylanders with Developmental Disabilities". 64 Active, 220 Inactive.
- 2009- Board Committees focus on services, public education, finance. 62 Active, 218 Inactive Members.
- 2011- Actuarial excel program developed to assist Board to structure fees for the future.  
Investment fund moved to Harbor Investment Advisory. 69 Active, 207 Inactive Members.
- 2012- Beverly Rill retired as Executive Director, Kathy Vecchioni hired. Office moved to Arc Baltimore.  
7 Personal Advocates serve 67 Members and 16 with Advocacy Plans. 204 Inactive Members
- 2013- Board sets fee for sibling sponsors, non-member services. Membership fee \$2400, \$3000 for sponsors over 65. 11 Advocates serve 65 Members, 28 Advocacy Plans. 205 inactive.
- 2014- With MD Developmental Disabilities Council and Arc Maryland, formed Maryland Sibling Network.  
Luanne Frebertshauser Family Advocacy Support Fund established. 14 Advocates served 65 Members, 39 Annual Advocacy Plans, 198 inactive members. Member fee \$3000, \$3500(65-74), \$4000(74+). Received \$153,000 Birkland Bequest and \$43,000 Safranek Bequest.
- 2015- "Planning for the Future of an Only Child" resource guide developed, co-sponsored sibling conference, met with UAE Delegation. 69 active members; 39 advocacy plans. 194 Inactive.
- 2016- Awarded Baltimore County Commission on Disabilities Family Support Award and Maryland State Legislature Citation. 68 Active members. 35 Annual Advocacy plans. 197 inactive members.
- 2017- 15 Advocates serve 93 Active members. 41 Annual Advocacy plans. 168 inactive members.
- 2018- Enrichment Assessment pilot begins. Received \$64,000 Grayson Bequest and \$10,000 Haffman Bequest. 15 Advocates, 86 Active members, 49 Annual Advocacy Plans, 169 inactive members.



## MISSION STATEMENT

*By Their Side guides families and provides advocacy for Marylanders with developmental disabilities. By Their Side believes everyone deserves respect, choices, and quality of life. We support our mission by*

- ❖ Providing lifelong advocacy for those we serve;*
- ❖ Protecting the legal rights of each individual;*
- ❖ Guiding individuals and families through the maze of resources in the service delivery system; and*
- ❖ Assisting families with transition planning.*

## HOW YOU CAN HELP

- ❖ Sponsors, please establish a plan of notification eg instructions to the Executor of your Will, to assure timely start of By Their Side advocacy services.*
- ❖ Please pass along the introduction packet in your meeting folder. Follow the tradition of By Their Side's founding parents by informing others who may seek a service like By Their Side.*
- ❖ Volunteer to serve on the Board of Directors. New Board members bring new perspectives that help us grow.*
- ❖ Join By Their Side's Legacy Society. Like the Grayson and Haffmans families, consider naming By Their Side as a remainder beneficiary of a Special Needs Trust or in your will. Help secure future advocacy services and keep fees affordable.*
- ❖ Give the gift of Advocacy when you shop online. Amazon will donate to By Their Side when you select us and shop on their identical website, [smile.amazon.com](https://smile.amazon.com)*

**BY THEIR SIDE BUDGET FY 2018**

	<b>EXPENSES:</b>	BUDGET	ACTUAL TOTAL
1	PROGRAM:		
2	LIFELONG ADV	\$ 15,122.10	\$ 14,816.31
3	FAMILY SUPPT	\$ 8,088.40	\$ 8,251.21
4	ADV. SVC. PLAN	\$ 48,531.36	\$ 60,457.64
5	ADMIN. FEES	\$ 39,438.00	\$ 41,963.76
6	OFFICE SUPPLIES	\$ 1,000.00	\$ 775.17
7	INTERNET FEE	\$ 210.00	\$ 234.93
8	TELEPHONE	\$ -	\$ -
9	POSTAGE	\$ 220.00	\$ 435.96
10	PRINT/PUBL.	\$ 2,700.00	\$ 1,606.00
11	RENT	\$ 2,400.00	\$ 2,400.00
12	TRAVEL	\$ 2,037.10	\$ 1,915.41
13	AUDIT	\$ 5,050.00	\$ 5,000.00
14	REPAIRS	\$ -	\$ -
15	INSURANCE	\$ 2,950.00	\$ 5,931.24
16	BANK FEES	\$ 8,850.00	\$ 9,208.84
17	DUES	\$ -	\$ -
18	ANNUAL MTG	\$ 2,000.00	\$ 2,301.87
19	INKIND EXPENSE	\$ -	\$ -
20	EQUIPMENT	\$ -	\$ -
21	MISCELLANEOUS	\$ 100.00	\$ 435.00
22	FUNDRAISERS	\$ 500.00	\$ 1,072.00
23	PUBLIC EDUC.	\$ 4,850.00	\$ 5,207.37
24	PAYROLL TAXES	\$ 5,511.90	\$ 6,985.49
25	<b>TOTALS:</b>	<b>\$ 149,558.86</b>	<b>\$ 168,998.20</b>
	<b>INCOME:</b>		
26	INTEREST (IF)	\$ 16,500.00	\$ 25,654.88
27	ADV. SVC. PLAN	\$ 79,802.69	\$ 77,847.43
28	INKIND INCOME	\$ -	\$ -
29	FUNDRAISERS	\$ 10.00	\$ -
30	MISC. INCOME	\$ 100.00	\$ -
31	MTG TICKETS	\$ 1,000.00	\$ 1,400.00
32	CONTRIBUTIONS		\$ -
33	GENERAL	\$ 11,000.00	\$ 23,368.68
34	ACAF	\$ 3,000.00	\$ 400.00
35	ANNUAL MTG	\$ 1,250.00	\$ 1,375.00
36	MEMBER DUES	\$ 700.00	\$ 950.00
37	TRANS IN FROM IF	\$ 36,196.17	\$ 38,002.21
38	TRANS IN DONATION	\$ -	\$ -
39	<b>TOTALS:</b>	<b>\$ 149,558.86</b>	<b>\$ 168,998.20</b>

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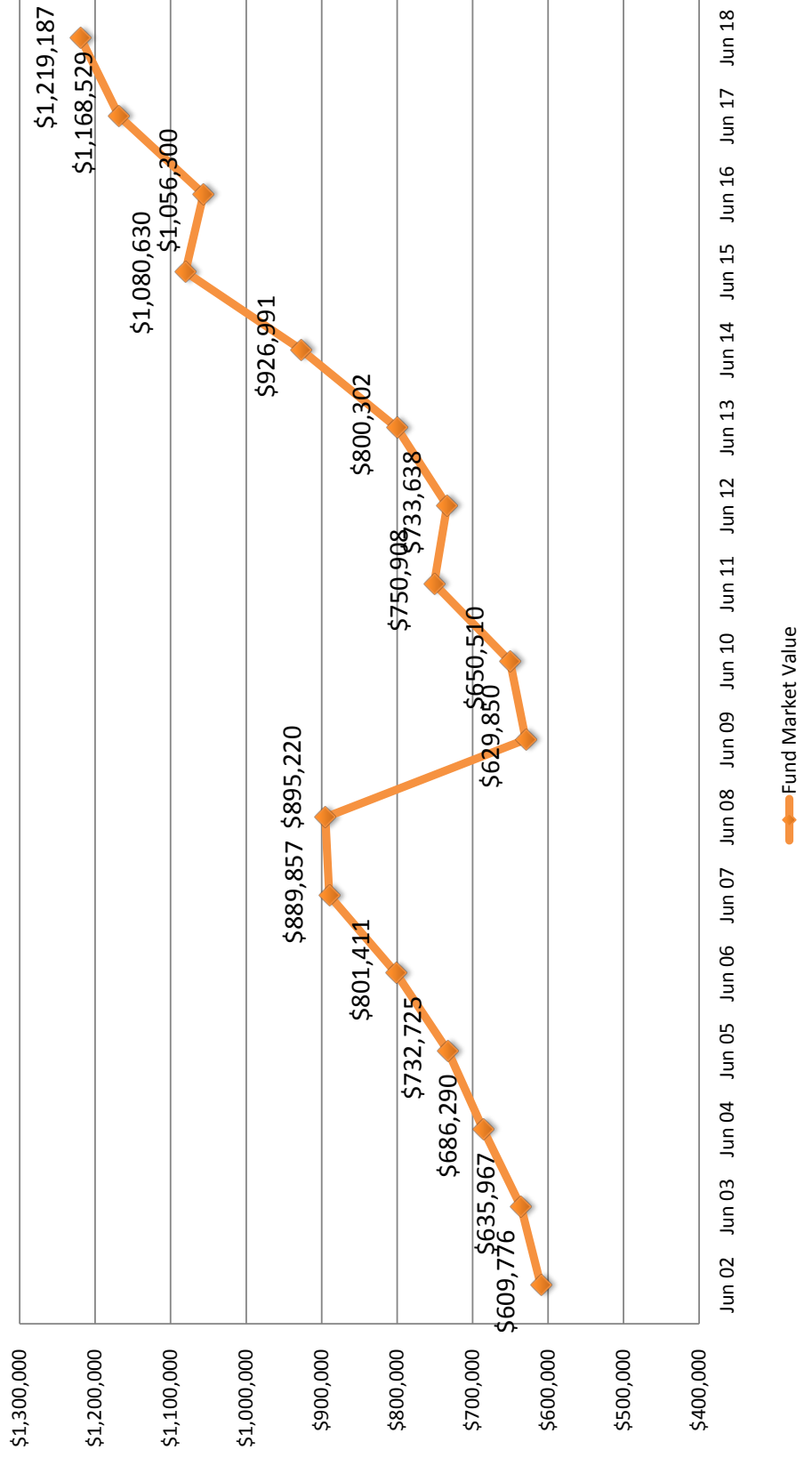
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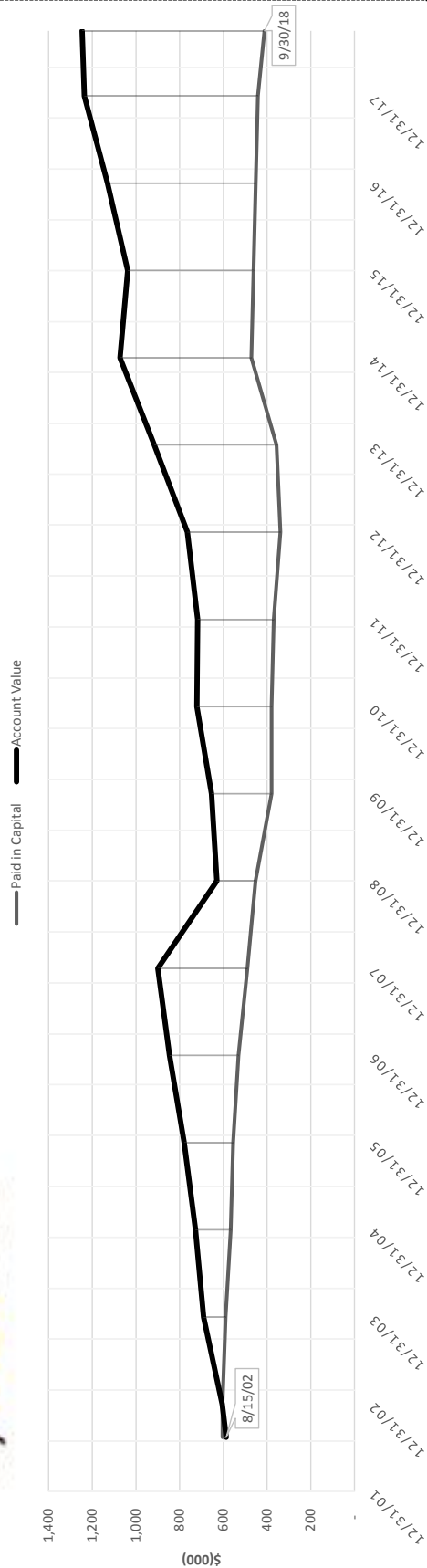


## Fund Market Value June Fiscal Year Ends





**Portfolio**  
**PAID IN CAPITAL & MARKET VALUE**  
*(Since Inception August 15, 2002)*



(\$000)	8/15/02	12/31/02	12/31/03	12/31/04	12/31/05	12/31/06	12/31/07	12/31/08	12/31/09	12/31/10	12/31/11	12/31/12	12/31/13	12/31/14	12/31/15	12/31/16	12/31/17	9/30/18
Paid in Capital	604	604	590	566	555	531	490	453	379	379	369	339	357	472	462	452	442	412
Unrealized Gain	(17)	1	100	162	224	315	410	177	275	342	349	426	559	601	576	678	795	835
Account Value	587	605	690	728	779	846	900	630	654	721	718	765	916	1,073	1,038	1,130	1,237	1,247

Unrealized Gain is the amount of market gain(loss) after fees & expenses. Paid in Capital is the sum of total contributions less total withdrawals. From inception to March 2011, data is from Deutsche Bank Alex. Brown (By Their Side provided) and March 2011 to present from Harbor Investment Advisory, LLC. By Their Side requested this information in this format. Please refer to the custody statements of Pershing LLC for the official records of the account.