



## South Shore Community Partners in Prevention

### South Shore Community Partners in Prevention (CHNA 23)

Wednesday, April 12, 2017

8:45 A.M. to 10:15 A.M.

Beth Israel Deaconess Hospital - Plymouth

Funkhouser Conference Room A

275 Sandwich Street, Plymouth

Minutes

In attendance:

<u>First Name</u>	<u>Last Name</u>	<u>Organization</u>	<u>E-mail</u>
Kim	Allen	SSCPP Coordinator/United Way of Greater Plymouth County	<a href="mailto:chna23@gmail.com">chna23@gmail.com</a>
Brianna	Arcaro	Bridgewater State University	<a href="mailto:briannaarcaro@icloud.com">briannaarcaro@icloud.com</a>
Maureen	Cavicchi	Dept. of Developmental Disabilities	<a href="mailto:Maureen.cavicchi@state.ma.us">Maureen.cavicchi@state.ma.us</a>
Donna	Ciappina	Duxbury Senior Center	<a href="mailto:donnaciappina@duxburycoa.com">donnaciappina@duxburycoa.com</a>
Jenna	Cohen	Bridgewater State University	<a href="mailto:J2cohen@student.bridgew">J2cohen@student.bridgew</a>
Brynn	Cooper	DMH Plymouth	<a href="mailto:Brynn.cooper@massmail.state.ma.us">Brynn.cooper@massmail.state.ma.us</a>
Marian	De la Cour	BID Plymouth	<a href="mailto:mdelacour@bidplymouth.org">mdelacour@bidplymouth.org</a>
Maureen	Doherty	BID Plymouth Hospital	<a href="mailto:mdoherty@bidplymouth.org">mdoherty@bidplymouth.org</a>
Tina	Dwyer	South Shore Health System	<a href="mailto:Katrina.Dwyer@sshosp.org">Katrina.Dwyer@sshosp.org</a>
Shawna	Fanning	High Point	<a href="mailto:sfanning@hptc.org">sfanning@hptc.org</a>
Ashley	Frazier	BID Plymouth ACCESS	<a href="mailto:afrazier@bidplymouth.org">afrazier@bidplymouth.org</a>
Mary	Hammond	Care One	<a href="mailto:mhammond@care-one.com">mhammond@care-one.com</a>
Russ	Illes	Magic Hat Project	<a href="mailto:ssur1@verizon.net">ssur1@verizon.net</a>

#### CHNA 23: South Shore Community Partners in Prevention

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[chna23@gmail.com](mailto:chna23@gmail.com)

[www.chna23.org](http://www.chna23.org)

Mike	Jackman	Congressman Keating, SSCPP Chair	<a href="mailto:Michael.Jackman@mail.house.gov">Michael.Jackman@mail.house.gov</a>
Amy	LeFort	SAPC	<a href="mailto:alefort@hptc.org">alefort@hptc.org</a>
Heidi & Greg	MacCurtain	DDS/Panelists	
Barb	Meehan	Caregiver/ Alzheimer's Association	<a href="mailto:bamscats@gmail.com">bamscats@gmail.com</a>
Shelby	Pedzewick	Duxbury Senior Center	<a href="mailto:shelbypedzewick@yahoo.com">shelbypedzewick@yahoo.com</a>
Deb	Schopperle	BID Plymouth	<a href="mailto:dschopperle@bidplymouth.org">dschopperle@bidplymouth.org</a>
Kathleen	Small	Marshfield COA	<a href="mailto:ksmall@bridgew.edu">ksmall@bridgew.edu</a>
Amy	Sylvia	SSWRC- Road to Healing	<a href="mailto:Amy.sswrc@hptc.org">Amy.sswrc@hptc.org</a>
Susan	West	BID Hospital Plymouth	<a href="mailto:SM.West@verizon.net">SM.West@verizon.net</a>
Chris	White	Road to Responsibility	<a href="mailto:cwhite@rtrinc.org">cwhite@rtrinc.org</a>

Meeting called to order by Mike Jackman, SSCPP Chair at 9:00a.m. Everyone was welcomed and gave self-introductions.

Minutes for the March 8th SSCPP general meeting were approved unanimously by all in attendance.

Panel: Caregiver Burden

Panelists: Heidi and Gregg MacCurtain, Parents of a Young Child with Leigh's Disease

Barbara Meehan, Advocate for Alzheimer's Association of MA/NH

Rev. Dale Thackeray, BID-Plymouth Hospital Chaplain & Oncology Caregiver

Mike introduced panelists and all were given the opportunity to share and respond to questions.

Heidi & Greg

- Heidi and Greg are the parents of Abby. Abby is a happy and adventurous 6 year old living with Leigh's Disease. Leigh's is a mitochondrial disease and most individuals rarely live into their teens.
- When Abby was first born, noticed some things but chalked these up to new parents' anxiety. Noticed an issue at 10 months and did not get the information needed from doctors. Hospital did not have all of the answers in regards to Leigh's and it was very hard to find help and resources.
- Currently travel to Ohio every 3 months for a drug study.

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- Have reached out to social groups, but still not a lot of support.
- Signed up for Google Alerts on Leigh's Disease to get the latest information.
- Working full time and having a second child make it very hard to find the time to fill out all of the paperwork required.

### Barbara

- Barbara is an Alzheimer's advocate and is passionate about awareness and advocacy. Her partner first developed memory issues in 2007 and Barbara was by her side for the duration of the illness.
- It took some time to get a diagnosis and were not given much other information at the time of diagnosis. Got referred to someone to sort out legal and financial issues, but was otherwise on her own.
- Found the worst part was not being directed as to where to start- no help given with initial diagnosis. This caused Barb to miss out on resources. Navigating alone was very hard.
- Found a support group that worked for her 3 years into illness. Found the group was a big help- nice to have people to relate with and laugh with.
- Since her partner's diagnosis in 2007, feel Alzheimer's awareness has started to improve.
- Suggests looking into healthcare proxy, power of attorney, and talking to loved ones about end of life issues so a plan can be made in advance.
- Promoted Alzheimer's Association 24 hour helpline with help in multiple languages: 800.272.3900

### Dale

- Provides care at BID Plymouth. Co-facilitates, with Kathy Horsman, a caregivers group and stage 4 cancer group. Groups meet twice a month in the oncology conference room.
- Cancer Center has a 24 hour hotline as well.
- Have a confidential environment that is safe. Usually see 1-8 people per meeting and never cancel meetings.
- Some come with spouses; have seen young adults caring for parents, etc.
- BID provides a holistic approach to cancer. Also have a cancer survivors group.
- Caregivers often say the focus is on the patient, so BID asks how the caregivers are doing.
- See every state of caregiver- from just diagnosed to years in.
- Feels overall education about illness, connecting people to their support team, and talking about what is coming in the future are key and what healthcare could be doing better.
- Has found some patients do not have spiritual needs, but their caregivers do.

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Discussed navigating the system, barriers to accessing care, and the importance of health literacy and communication with healthcare providers.

Mike and Marian shared Medline Plus, by the National Library of Medicine, as a resource. This resource was emphasized at a plain language training SSCPP recently attended.

All panelists agreed Congressman Keating has been a big help and advocate.

The floor was opened for questions and discussion with panelists.

Upcoming SSCPP Events (details on our website at [www.chna23.org/calendar](http://www.chna23.org/calendar)):

May 16th- A Conversation About Removing Obstacles to HealthCare for People with Disabilities

May 17<sup>th</sup>- SSCPP sponsors “Laughter is the Best Medicine” Comedy Night on Breaking Down the Stigma of Mental Health

May 18<sup>th</sup>- Marian De La Cour, Medical Librarian at BID Plymouth and SSCPP steering committee member will be presenting a training on Untangling the Web on Consumer Health Information.

The floor was opened for agency announcements.

The next meeting is scheduled for **May 10<sup>th</sup>**. The topic will be mental health.

Respectfully submitted by Kimberly Allen  
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