

Dear COYOD,

As Children Of those with Young Onset Dementia (COYOD), you've had to navigate through complex emotional, financial and legal challenges that follow such a diagnosis. If your experience has been anything like ours, you likely found yourself in need of support and resources, and at such a young age, have often felt alone in your struggle to support your family member. As COYOD we always felt a step behind and struggled with maintaining a level of normalcy, holding onto our youth and not losing sight of joy in life. Only now, three years after the diagnosis of our loved one, have we realized how many other young people are faced with the effects of this daunting disease. Motivated by our personal experience with Young Onset Dementia and meeting other COYOD, we created the project Spoke Your Mind to build a community of support. We at Spoke Your Mind need to meet COYOD like you, either in-person or online, to share stories and resources.

Created by us, cofounders Max Larkin and Emily Boardway, Spoke Your Mind was inspired by the Young Onset Alzheimer's diagnosis of Max's father, Dr. Hugh A. Larkin II, in 2006; he was just 56 at the time. Dr. Larkin is one of the estimated half million people the United States living with Young Onset Alzheimer's and related dementia, which affects people before age 65. The goal of Spoke Your Mind is to spotlight personal narratives on film and build an online forum at [spokeyourmind.org](http://spokeyourmind.org) to connect COYOD. The majority of the filming will take place during a 5,000-mile bicycle tour across the U.S. to many COYOD's respective communities beginning in May. For route details, visit [spokeyourmind.org](http://spokeyourmind.org). Spoke Your Mind is a project of Mind Series, a nonprofit created to promote public health through art and compel communities to act.

### **So how can you help?**

#### **On the Road**

We need support of all kinds during our "bike messenger" journey! Finding COYOD willing to meet up and share their narratives is our top priority. If inspired by the project, we welcome any kind of assistance you can give. This includes recruiting other COYOD; hosting a Spoke Your Mind meeting while we're in town; offering a yard, floor, couch, bed or other accommodations; or making a donation. Please check out the route and timeline here: [spokeyourmind.org/bike-tour](http://spokeyourmind.org/bike-tour)

#### **On Film**

Share your story on camera. Footage will be made into SpokeTube shorts to be posted on [spokeyourmind.org](http://spokeyourmind.org) as well as possible use in a full-length documentary. We'll be happy with whatever level of involvement you and your loved ones are comfortable with. Check out Spoketube here: [spokeyourmind.org/spoketube](http://spokeyourmind.org/spoketube)

#### **Online**

The best way to ensure a national network of support for COYOD is to join it! By going to [spokeyourmind.org](http://spokeyourmind.org) and creating a profile to share stories, photos and videos as well as health, financial and legal resources, you'll be letting others know they aren't alone! Explore the website and other COYOD profiles here: [www.spokeyourmind.org/coyod-resources](http://www.spokeyourmind.org/coyod-resources)

As COYOD we can really make a difference. Providing a platform for COYOD to share stories will offer a place for COYOD to turn to when they feel alone in the struggle just as we did. In addition, by spotlighting COYOD narratives through film others will be hit with the realization that dementia is no throw away disease affecting only the elderly, but a thief that too steals the lives of the young.

So let us unite!

Please contact Max at [max@mindseries.org](mailto:max@mindseries.org) (253.381.6866) or Emily at [emily@mindseries.org](mailto:emily@mindseries.org) (253.226.5561).

We look forward to meeting you!

Very best,  
Max and Emily