

Testimony

Denise Lopez-Majano

In keeping with Speak Up About ME's goal to highlight young people with ME/CFS, I put out a request for early ME/CFS onset (under 22 at onset) information. I asked for age at onset, age at diagnosis and current age.

The request was heard (and answered from) around the world.

Some people specified that a nickname or first name only be used. They fear repercussions from the medical community, from insurers and from others if they use their full name.

Many of the people on this list live in the US. In those cases that a different country was specified, I have included it.

Some of these people are here today and are providing testimony for CFSAC (many for the first time).

Many cannot be here in person – they are too ill, and/or they don't have the money to do so, and/or they don't have someone who can accompany them and so on. Some of these young people and their families have provided testimony as well.

| Name | Age at onset | Age at diagnosis | Current age | Country |
|------------------------|--------------|------------------|-------------|---------|
| Toby Vokal | 18 | 26 | 33 | - |
| Alexander Lopez-Majano | 14 | 15 | almost 20 | - |
| Matthew Lopez-Majano | 12 | 12 | 18 | - |
| Christina Gustavsson | 9 | 10 | 15 | - |
| Haley M. Bieber | 10 | 13 | 16 | - |
| Craig Jackson | 6 | 8 | 13 | - |
| Jamie Jackson | 10 | 10 | 16 | - |
| Janine Militello | 13 | 15 | 17 | - |
| Marc Tillinghast | 15 | 35 | 45 | - |

| | | | | |
|---------------------|--------|-----------|----------------------|---|
| Brian Bernard | 11.5 | nearly 12 | 17 | - |
| Cort Johnson | 18 | 25 | 51 | - |
| Casey Ryan Fero | 8 | 9 | died 2005, age 22 | - |
| Rebekah Bolton | 12 | 17 | 18 | - |
| Scott McConnell | 12 | 12 | 36 | - |
| Jessica Horton | 18 | 20 | 25 | - |
| Elizabeth Regan | 12 | 13 | 25 | - |
| Stephanie Moulton | 16 | 20 | 21 | - |
| Mary Kier | 12 | 29 | 52 | - |
| Keith Baker | 17 | 17 | 41 | - |
| Barton Baker | 13 | 13 | 36 | - |
| S. Siobhan McElwee | 18 | 47 | 49 | - |
| Barbara Spivey | 13 | 17 | 26 | - |
| Three Lost Decades | 20 | 31 | 54 | - |
| Jennifer B | 7 | 15 | 34 | |
| Lori Meehan | 15 | 17 | 25 | - |
| Cari Allhouse | 11 | 14.5 | 37 | - |
| Elizabeth | 13 | 15 | 38, she is well | - |
| Timothy Waud | 12 | 12 | 24 | - |
| Alex Auron | 12 | 13 | 17 | - |
| Natalie Stein | 14 | 14 | 16 | - |
| Sofia Stein | 12 | 12 | 14 | - |
| Johnny Duncan | 16 | 20/21 | 26 | - |
| Alexis Gallinger | 15 | 17 | 19 | - |
| Megan Draghi | 14 | 14 | 15 | - |
| Rebecca Childs | 13 | 14 | died, age 23 | - |
| Harriet Watson | 14 | 24 | 44 | - |
| Henry N. Farnham | 16 | 20 | 22 | - |
| Aliza Nehls | 13y 4m | 13y 10m | 15y 6m | - |
| Kathryn Ozog | 12 | 13 | 24 | - |
| Deb Friedman | 17 | 24 | 36 | - |
| Benjamin DiPasquale | 18 | 20 | 22 | - |
| Lindsey Dunlap | 17 | 17 | 24 | - |

| | | | | |
|--|-------|-------|------------|----------------------------|
| Patrick Holaday | 12 | 17/18 | 37 | - |
| Zaid Haider Ajina | 7 | 20 | 23 | - |
| Sophie Thorpe | 9 | 9 | 15 | - |
| Janelle Wiley | 19 | 28 | 32 | - |
| Angela Congdon sister Janelle Wiley | 6.5 | 20 | 34 | - |
| Michelle Klein | 16 | 19 | 22 | - |
| Colleen Stanturf | 11 | 17 | 43 | - |
| Rachel Smith | 6 3/4 | 7 | 27 1/2 | - |
| Melissa (McLaughlin) | 15 | 15 | 31 | - |
| Holley H. Eguileor | 12 | 30 | 38 | - |
| Rachel | 17 | 17 | 21 | - |
| Danielle Bradley | 14 | 18 | 19 | - |
| Jen | 14 | 17 | 41 | - |
| Karen Sanjanwala | 18 | 19 | 25 | - |
| Wendy | 22 | 23 | 28 | - |
| Meagan Brejcha | 12 | 21 | 23 | - |
| Erin Monteith | 11 | 18 | 25 | - |
| Jessica | 14 | 14 | 17 | - |
| Michael Newton | 10 | 11 | 15 | - |
| Rebecca Bailey | 20 | 22 | 37 | |
| Kimberly Olt | 16 | 36 | 50 | - |
| Austin Craver | 15 | 16 | 17 | - |
| Tom Kindlon | 16 | 22 | 38 | Ireland |
| Gail Torrens | 8 | 32 | 35 | N.Ireland |
| Fiona Jane Ross | 14 | 18 | 20 | Scotland |
| Elizabeth Moon | 12 | 27 | 40 | England |
| Jemma Purdy | 14 | 19 | 20 | Thirsk N.Yorkshire England |
| Kate Hutchinson | 16 | 17 | 23 | Australia |
| Nicole Sander | 16 | 16 | 21 | Australia |
| Josie Eldred | 13 | 13 | 20 | Australia |
| Zoe | 8 | 9 | 31 | Australia |
| Sergio | 21 | 21 | 28 | Spain |
| Sheila Gust | 14 | 15 | 21 | Canada |
| Siobhan | 21 | 23 | 42, fairly | Canada |

| | | | | |
|---|-------|----|-------------------------------|--------|
| | | | well, except postinfection | |
| Marie-Laure Arsac-Shea | 11 | 21 | 23 | Canada |
| Erin Pressner whose birthday is May 12th HAPPY BIRTHDAY ERIN! | 15/16 | 21 | 22 | Canada |

Matthew recently said to me

“I’m 12.
I should be 18,
but I’ve lost 6 years of my life to ME/CFS.”

Erin Pressner has given me permission to use this quote about what it is like to be a young person with ME/CFS.

"We're supposed to be out creating ourselves and meeting people and learning and working,
but we're not able to do any of that. It's as if our whole lives have been put on hold
and
all we can do is try anything, ----- and everything, ----- and wait. "

We (our government, its agencies, and as a nation)
must increase awareness
of the impediments ME/CFS imposes on learning *as well as on earning*,
of the isolation created by ME/CFS, and
of the way ME/CFS prevents people from having a normal, independent life.

We **must** require ongoing education for medical professionals about ME/CFS and its devastating impact on lives.

We **must** promote a better understanding of ME/CFS. Doing so will demonstrate the urgent need for increased research (and increased funding for research) - that must be on par with disease prevalence and severity - to solve and treat ME/CFS.

Thank you,
Denise Lopez-Majano