SPECIAL NEEDS ALLIANCE

Recommended Books for the Special Needs Community, Second Installment

The Voice is the e-mail newsletter of The Special Needs Alliance. This installment was written by Special Needs Alliance member Laurie Hanson, Esq., a shareholder in the Minneapolis, Minnesota elder law firm of Long, Reher, Hanson, & Price, P.A. The firm's focus is to provide individuals who are aging or living with disabilities positive strategies to live as independently as possible for as long as possible. Laurie concentrates her practice exclusively in the areas of government benefit eligibility, special needs trusts, trust and public benefit litigation, estate planning and planning for incapacity. She is a past president of the Elder Law Section of the Minnesota State Bar Association, a member of the SNA board of directors, and is repeatedly named a super lawyer in the field of elder law by her peers.

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As lawyers with elder and disability practices, Special Needs Alliance members often meet with clients who have a disability or disease that is new to them. Our practice is to read about the disability before the client comes to the office, so that we have an understanding as to the special needs that client may have, and then the appropriate planning and referrals to make.

In our effort to broaden our wealth of information about disabilities and diseases, and to deepen the understanding of each Alliance member about different conditions and circumstances, we have an active "special needs" book group. Twice each year, we undertake to read one book about a different disability. In January, 2015 the first installment of Recommended Books was published, reviewing books we read from 2010-2014. In this installment, you will find a review of the books we have read since the first installment.

I find myself recommending most of these books to my clients, when appropriate, – be it mental illness, Huntington's, Down Syndrome, or Alzheimer's,... over and over again. I keep a copy (or two) of each book in my office so that I can lend them out. Our clients find solace between the pages just knowing they are not alone or seeing things from a different perspective. These books can give words to difficult feelings and hope when there feels like there is none. Reading a great book that speaks to a client's circumstance can be akin to attending a private support group.

For anyone touched by illness or disability, or really, for everyone (because you may someday be touched by illness or disability), these books can be a common ground for *understanding and support. We think maybe our reading can help others find an entrance to the literature of special needs. We encourage others to sample from our reading list.*

Special Needs Alliance Book Club History March 2015 – March 2018.

Spring, 2015 – Autism/Asperger's before there was a recognized diagnosis

***A Confederacy of Dunces** by **John Kennedy Toole** (1980). The central character of this book is Ignatius J. Reilly, an educated 30-year-old man living with his mother in early-1960s New Orleans. He has trouble with cleanliness, personal hygiene, employment, social cues, and friendships, and will pontificate endlessly to anyone who will listen about his philosophies of life. Ignatius's own view is that he is not of this world, and the story with many sub-plots and wild characters rings true for parents of adults with an autism spectrum diagnosis. A bronze statue of Ignatius J. Reilly can be found under the clock outside the Hyatt French Quarter Hotel (where the SNA had its spring conference in 2015) which is on the former site of the D.H. Holmes Department Store and the opening scene of the book.*

Fall, 2015 – Science Fiction dealing with locked-in Syndrome

***Lock-In** by **John Scalzi** (2014). This is a who-done-it FBI crime story. The main character is Chris Shane, an FBI agent with "Haden's Syndrome," caused by a virus that for only one percent of those exposed caused victims (called Hadens) to be fully awake, but unable to move or respond to stimulus. This resembles the real condition known as locked-in syndrome. Humanoid robotic personal transport units controlled by a Haden's brain (nicknamed "Threeps" after C-3PO in Star Wars) are developed as the primary way for a Haden to interact with the outside world. We never learn the sex of the main character, making the world of Hadens bodiless and sexless. The story is fast paced and a great read. What if technology could "unlock" the brain and allow people to live full lives?*

Spring, 2016 – Leprosy

***Moloka'i** by **Alan Brennert** (2003). This is an historical novel that chronicles the history of Rachel Kalama, who is diagnosed with Leprosy when she is seven and is sent by the government to the Kalaupapa Leprosy settlement on the island of Molokai in 1891. The novel spans Rachel's life from the age of five through her death in 1974, chronicling her solo journey to Moloka'i, her friendships, the Catholic priests and nuns who ran the settlement, her marriage, the birth of a child, and more. The settlement was active from 1865 until the 1940's when antibiotics were found to cure the disease. Residents were allowed to stay if they wanted, and now there are no people with Leprosy living on the island. Rachel left the island for 20 years, but ultimately returned to Kaluapapa to die and be buried. The novel is instructive as it chronicles Hawaiian history, how populations manage infectious diseases,* *and the buoyancy of the human condition. I think this was my favorite book of all of these the books the SNA Book Club has read so far.*

Fall, 2016 – Asperger's and Autism

Love That Boy, What Two Presidents Eight Road Trips, and My Son Taught Me About a Parent's Expectations *by* ***Ron Fournier*** *(2016). This book is the story of a father's journey to understand and bond with his son who was diagnosed with Asperger's syndrome when he was 12. The author is a journalist, who worked in the Washington Bureau of the Associated Press during the Clinton and George W. Bush administrations and was able, then, to take road trips with his son, a presidential history buff, to meet privately with Presidents Clinton, Bush, and Obama. The book is insightful for parents raising a child on the Autism-Asperger-non-neotypical spectrum. Fears and expectations, joys and wonders abound.*

Spring, 2017 – Physical Deformities

Wonder *by* ***RJ Palacio*** *(2012). August or "Auggie" Pullman, is a ten-year-old boy living with his mother, father, sister, and dog in New York City. He was born with a facial deformity which makes him an object of curiosity to all he encounters – just because of the way he looks. Auggie was home schooled until he turned 10. This story is about his first year in a private school but the story, as told by Auggie, his family, and some of his and his sister's friends, is of his whole life. It is a story that deals with bullying, friendship, redemption, and wonder. This is a great book for school children and adults alike.*

Fall, 2017 – Huntington's Disease

Inside the O'Briens *by* ***Lisa Genova*** *(2015). Joe O'Brien is a 44-year-old Boston police officer from the Irish Catholic neighborhood of Charlestown, Massachusetts. He is a devoted husband and father and a respected police officer. Slowly, he begins to have bouts of dementia, aggressive and violent behavior, and involuntary movements. Until he is finally diagnosed with Huntington's disease, his family and co-workers believe he is drinking, even on the job. Ultimately, he loses his job and struggles to maintain his identity and sense of purpose – and his family struggles as well – both for their father's illness, and for themselves.*

This story is a heart-felt and highly accurate study of Huntington 's disease, a lethal neurodegenerative genetic disease with no treatment to slow the progression of the disease and has no cure. Each of Joe's four children has a 50% chance of inheriting their father's disease, and a simple blood test can reveal their genetic fate. While watching their potential future in their father's escalating symptoms, each child struggles with whether or *not to have the genetic test which will confirm whether or not he or she has inherited the disease. If inherited, there is a 100% chance that symptoms will develop.*

Spring, 2018 – Multiple Physical Disabilities

Too Late to Die Young: Nearly True Tales from a Life *by* ***Harriet McBryde Johnson*** *(2005). This is a memoir written by the late* ***McBryde Johnson*** *(July 8, 1957 – June 4, 2008), who was an author, attorney, and disability rights activist. She was disabled due to a congenital neuromuscular disease, and required long term care supports and services her entire life. Nevertheless, she debated Pete Seeger, marched in Havana, was a chair of the Democratic Party in Charleston, SC, and was a constant voice for the rights of people living with disabilities. We read this book because it was recommended by Gaelynn Lea, a violin player and disability rights activist (https://violinscratches.com/) who was our main speaker at the March, 2018 meeting in San Diego. Gaelynn was born with Osteogenesis Imperfecta, a genetic condition that causes complications in the development of bones and limbs resulting in physical disabilities much like McBryde Johnson's. She cites this book as her inspiration to become a disability rights advocate. Both women are extremely talented and have inspired many.*
