

## KEEPING UP WITH CLAYBURGH

By Jeffrey Symes  
One Sky

It's hard to keep up with Michael Clayburgh. To accomplish half of what he does on a weekly basis would be enough for many people. In fact, his efforts could have far-reaching effects in the world of Alzheimer's research.

In the meantime, Clayburgh holds down three jobs, volunteers every week with the Portsmouth Police, plays guitar and basketball, and had been skiing every year for almost 20 years until he broke his back last year. But it's hard to stop Clayburgh completely - fully healed, he's switched to snowshoes this winter.

As much as he keeps a hard-working, active lifestyle, it is Clayburgh's genetic code that landed him a role in a drug trial at Mass General Hospital. With an extra copy of chromosome 21, Clayburgh has one of the most commonly occurring chromosomal conditions - Down syndrome. About one in 700 babies in the United States are born with Down syndrome - about 6,000 each year.

Clayburgh and his parents, Jim, a retired Seacoast cardiologist, and Nancy, a member of the board of directors for One Sky Community Services, found a welcoming community of people on the Seacoast who included their son in any activity he was interested in.

"We're very lucky to live where we live," says Nancy. "We were never told, 'We can't take him.' People here are very accepting."



MICHAEL CLAYBURGH

Clayburgh was also accepted into a two-year study at Mass General that could lead to a vaccine to prevent Alzheimer's in people with Down syndrome. The chromosome 21 that is duplicated in people with Down syndrome also carries a gene for amyloid precursor protein (APP) thought to be involved in the onset of dementia and Alzheimer's symptoms. By age 40, about 40 percent of those with Down syndrome develop Alzheimer's-like symptoms and that number increases to 50 percent by the age of 50.

Beginning last year, Clayburgh has been getting monthly injections at Mass General as part of the study. By the time he winds up his participation in the two-year trial next spring, Clayburgh will celebrate his 30th birthday having undergone a half-dozen MRIs and some two dozen physical exams to go along with a collection of psychological assessments. Most importantly, he will have had regular injections of either a placebo or the target drug to test its efficacy and any possible side effects.

In the meantime, life goes on as usual for Clayburgh, which means a working life that reveals him to be a steady, reliable employee. Clayburgh has been working weekends at



MICHAEL CLAYBURGH WITH HIS PARENTS, JIM AND NANCY.

McDonald's for the past 13 years, Dunkin' Donuts every Thursday for eight years, and Target on Tuesdays and Wednesdays for about eight years. And yet - "I want a new job," he says, because three are not enough.

Clayburgh still finds time to take guitar lessons at the Portsmouth Music and Arts Center and participate in basketball, bowling, and track and field with Special Olympics. And since he broke his back skiing last year, he'll be on snowshoes for the upcoming Special Olympics this winter. The cold doesn't bother him. He looks forward to every Super Bowl Sunday in February because that day happens to be shared with the annual Penguin Plunge fundraiser for Special Olympics. Clayburgh has taken that plunge every year for the past eight years.

"He's very outgoing and friendly," says Nancy, laughing with her husband. "Sometimes he goes out more than we do."

Last month, Clayburgh joined his older sister, Jackie, in attending their cousin's wedding in Bismarck, North Dakota. Younger sister, Diana, is an audiologist with the VA in Alaska who shared her story with him about the recent earthquake and a patient who thought it was part of his hearing test.

For all that he does and has accomplished, Clayburgh still has dreams of playing guitar for a big audience and talks about his hope of having a girlfriend one day. It seems Clayburgh will always have time to give to others. And what he gives is everything he is. As he says, "I sing songs from my heart."



*Incorporated in 1983, One Sky Community Services has been dedicated to providing a comprehensive array of services, supports and programs to individuals and families with intellectual and developmental disabilities, as well as acquired brain disorders. A private 5013C nonprofit organization, it is the designated area agency serving the following communities: Brentwood, Deerfield, East Kingston, Epping, Exeter, Fremont, Greenland, Hampton, Hampton Falls, Kensington, Kingston, New Castle, Newfields, Newington, Newmarket, North Hampton, Northwood, Nottingham, Portsmouth, Raymond, Rye, Seabrook, South Hampton and Stratham. One Sky works with nearly 1,200 individuals and families on a yearly basis.*