



## Living with Mowat-Wilson Syndrome (MWS)

### A brief history of challenges, interventions, and milestones

By Gannet's mother, Amy Hosa

Mowat-Wilson Syndrome is caused by a mutation or absence of a particular gene located on a chromosome that produces a protein that regulates the action of other genes, many of which are involved in development. You can find out more information about MWS at [www.mowat-wilson.org](http://www.mowat-wilson.org).

Gannet was born in 1981, long before Drs. Mowat and Wilson published their findings as Mowat-Wilson Syndrome (MWS) in 1998. It wasn't until 2005, when Gannet was 24, that his doctors matched this genetic syndrome to his profile.

*When Gannet was little, I would wonder what the future would bring. I was fascinated to get a glimpse of a trajectory or an adult world that had parallels to G's challenges...like a glimpse into a crystal ball. I hope that this glimpse into Gannet's world helps you find something about yourself or a person you know, and that it gives you a positive message about possibilities.*

### Finding community (Pre-MWS)

Without a known cause for disability, Gannet was known as "the puzzle baby." His neurological and developmental behavior paralleled that of the **deaf-blind and severe autistic** populations. The strategies and interventions for neuro-sensory training, social and practical self-help skills, and communication for deaf-blind and autistic children offered the best insights to the variety of sensory, therapeutic and educational approaches that proved to be very beneficial to Gannet's success. We joined forces with other families within this community to support and mentor each other. We all went to workshops to learn about our kids' needs and rights, became advocates, and participated on local and state committees on disability as well.

In hindsight, having raised a child with a severe disability, there's good news and bad news in not having a specific label. On one hand, I admit that the unknown disability caused us to experience roller-coaster anxiety because Gannet's progress was so divergent from milestones and norms, but on the other hand, I believe that the unknowns allowed everybody the flexibility to explore a wider variety of solutions and interventions without our sights being limited to "the

expected outcomes” of a particular syndrome. Don’t ever let anybody set finite limits for potential.

**Finding Balance:** Taking care of Gannet and the being involved in community organizations took a lot of our time, but not all of it. Working full-time and having a career, making art and spending time with friends kept me sane.

## A Lifetime of Milestones



**Trusting that change will happen:** For Gannet, each tiny step towards a goal took years, not months. Some days it was difficult for us to ignore all the missed milestones and remain confident that all the stimulation and exercise was helping the brain and body “rewire.” But, then one day something clicks, and a tiny step is achieved. Success is sweet no matter how great or small.

*The following is an attempt to present a tiny slice, as a snapshot of various stages of Gannet’s life from birth to adult.*

### Age 0-3



**The Diagnosis (pre MWS):** At birth, the doctors noted a number of physical anomalies – like low rotated ears, and a hypospadias (twisted penis with the urethra opening on the side) – that could, or might not, point to more serious problems. Gannet was hospitalized twice for a failure to thrive in the first 4 weeks. Hirschsprungs was discovered and a colostomy followed.

When it came to filling out forms, the doctors wrote: **cerebral palsy, developmental delay, legally blind, no speech**. A detailed list of medical terms from their reports includes: static encephalopathy, Hirschsprungs Disease resulting in a colostomy at 4 weeks old, hypospadias, agenesis of the corpus callosum, severe developmental delay, grand mal seizures, left focal (right brain origin) with left body Todds paralysis following and frontal lobe seizures (both controlled by meds), non-verbal, legally blind (diminished vision and hearing of cortical origin), nystagmus and strabismus along with marked esotropia in right eye, eventually cataracts in both eyes (lenses replaced), cerebral palsy, spastic hyper tonus in all four extremities, hyperactive DTRs in the LEs and normoactive in the UEs.

**Vision (Age 0-3):** Gannet only looks at bright windowpanes and lights. At first the ophthalmologist suspects that Gannet is blind, and refers us to the Blind Babies Variety Club. At 6 months, data from sensors hooked up to his visual cortex conclude that images are being received, but the diagnosis is legally blind because the neurological processing of the images is not working. I was told to “teach your son to see,” to help him give meaning to his visual world. With help from Blind Babies we spend years on visual training using light boxes (pictured below) for focus and recognition along with brightly colored objects in motion for tracking. We assist G to connect what his eyes are seeing to what his hands are doing while explaining every task and outcome to him. The hope is that this “training” will stimulate neurological connections to rewire the brain to create meaning, eye-hand coordination and object recognition.



**Hearing vs Vision (Age 0-3)::** There is no sign that G recognizes his dad or me visually as different from any other person, even if we put our face right in front of his. However, by age two he reacts to the sound of our voices and greets us with absolute glee. This is reassuring, to say the least. It's obvious that Gannet is using his peripheral vision to find things – like his bottle of milk or spoon on the tray - but he makes only the briefest glance, then averts his eyes before he reaches for the object. Eye-hand coordination and hearing are beginning to mature in slightly unorthodox ways.

**Communication (Age 0-3):** From friends with deaf/blind kids, we learn how it's best to reinforce all input as a **multiple sensory experience**, even

communication. I learn the basics of “See Sign” (an alternative to American Sign Language) and convert the hand movements to tactile signing, by making the signs on G’s body, or taking his hands in mine. We make the signs together as I speak the words. We are told to talk to G constantly as if he understands everything that we say.

No spoken language is developing. Vocalizations and babbling are rare. At about age 3 Gannet begins to chortle happily and babble when we put him to bed and there is quite a repertoire of sounds like “ta, da, “ba,” and “mumum ” being expressed with a musical voice as if telling a story. We think he is making a “mk” sound for milk and “woo” for our dog Woody. All that disappears when he gets a bit older. Today “achoo” and “mumum” and “buh” are his words that have many meanings depending on context.

**State Agencies and Funding:** Blind Babies Variety Club staff suggests that Gannet is at high risk for physical and developmental delays and will benefit from an infant early-intervention program. California has a system of state funded regional centers that distribute funding to agencies that serve people with disabilities. Gannet becomes one their clients and is assigned a case manager. Easter Seals is funded for their infant stimulation program, age 0-3.

**Physical Therapy and more: (Age 0-3):** Physical development is slow and all milestones are missed. Gannet is extremely floppy and can’t sit up. His body and face are a-symmetrical – the left side is sunken and weaker as if he’d had a stroke. The primary therapy model at Easter Seals is NDT (neuro-developmental training). The idea is to induce movement and weight bearing that simulates neural connections for what his body should be experiencing in normal development – like sitting up, crawling and standing – so his body will be prepared for the time that he is able to initiate movement on his own. Hand-over-hand we take him through the motions of crawling. Gannet is fitted with AFOs (braces) that support his foot and ankle for weight bearing for standing upright (with our support) and is learning to take steps. He holds both arms in a high-guard position – hands clenched at shoulder height. We work (for 2 decades) at relaxing them down with stretching and stroking.

**Learning Style (Age 0-3):** Gannet does not imitate or follow even the simplest imitation games like clapping or pat-a-cake. Participation is hand-over-hand with tactile and voice cues. In the long run, imitation has never been a style of learning for Gannet. He does not generalize either, rather the same skill needs to be reinforced in different contexts.

**Social Behavior (Age 0-3):** There is no direct eye contact, no interest in playing with others, but G seems to enjoy being around other children and adults. He is a

hard nut to crack. For the first few years you really had to be animated, jostling and bouncing him about, to get any kind of reaction like a smile.

**Sensory Processing (Age 0-3):** It seems like all of Gannet's senses are isolated from each other, and each works at a different speed. Response time to sensory input – like a bang, or touch – might be delayed by as much as 15 seconds. Over time that diminishes, and today cause and effect processing is almost simultaneous.

**Fine Motor (Age 0-3):** Everything is explored with his right thumb. It is either in his mouth or tap-tapping away on every surface (identifying things by texture and sound). G has little interest in developing fine motor skills using fingers for tasks such as picking up toys, exploring objects, or turning knobs. (Today, he still uses the primitive palm-and-finger grip for small items.) We encourage the use of other fingers, for example: Gannet and I sit at the piano (because the sound focuses his attention), and I isolate each finger and have him depress individual keys. He refuses to hold onto anything and will immediately fling it away. The exception is his bottle, drink cup, and spoon. A healthy appetite is a great motivator for refining these motor skills!

**Touch Defensive (Age 0-3):** G recoils from touching soft or furry things, live or stuffed, and solid food is not going to enter his mouth. Easter Seals therapists have us using a vibrator on his hands, cheeks and lips. To introduce solid foods, a soft triple-cream French cheese on a finger is to his liking, then cheese on soft bread, etc. (A few years later a Scottish friend was quickly shushed when he blurted out “My god, he eats like a Gannet” which is equal to the American “he eats like a pig.” Like his namesake, Gannet became a lover of food and a bottomless pit.)

## Age 3-5



**Public School:** Special Education classes start at 3 years old. Based on the intake assessment, Gannet is placed into a severely handicapped classroom. (By this time I wasn't daunted when the report concluded that my 3 year old “was

likely not going to drive a car.”) Workshops taught us about the legal rights of students, and the responsibilities of the school system. We gathered with other parents of deaf/blind and severely handicapped kids to work together on our IEPs (Individual Education Programs) We insist on language that describes our kids’ learning modality that includes multiple-sensory integration teaching techniques, direct services and training for parents and teachers (not just consultation) by vision, speech, mobility & orientation, PT and OT therapists, appropriate goals, and most important 1:1 aides. Gannet is in daycare after school and that staff is cross-trained in therapy and intervention by Easter Seals and now the school district staff.

**Physical (Age 3-5):** Gannet is able to lift himself up on his knees but does not crawl. By age 5 he’s learned to pull himself up on a piece of furniture to stand on his own but does not cruise. Movements and coordination are improved, but he cannot motor-plan fast enough to put his arms out to catch himself if falling – whether from a seated or standing position. (It’s still the case today.) Physical therapy to maintain full range of motion continues in earnest. At age 5 Gannet gets a walker and with much prodding will take a few steps, then stop. Steering is not a talent. He does not trust being vertical.

**Fine Motor – Sensory Integration (Age 3-5):** Before expecting G to participate in fine motor skills, we institute a 3-step intervention to break down his “high guard” stiffness, touch aversion and lack of eye contact. 1) Hand-over-hand we relax the shoulder and elbow joints and stretch his arms. 2) His hands are rubbed on his pant legs or clapped together to desensitize them to touch. 3) We cue him to “look at me” and catch his eye. Only then can an activity or educational lesson begin. Typical activities like coloring, sorting objects, dressing, getting a toy from a shelf, etc. are all hand-over-hand with verbal and visual prompts to cue him every step of the way. The exception is holding a big plastic truck upside down against his cheek while spinning its wheels, listening to the sound and feeling the vibrations. This becomes a passion and gives him much solace. G is getting better at functionally using his preferred thumb (for example to push a lever to play recorded music) and now he is expected to work on his pointer finger to use as a tool, and turning his wrist. The left side is still weaker, and two-handed tasks are worked into the game plan to improve bi-lateral coordination.

**Vision (Age 3-5):** EVERYthing we present to him is cued by a “look” and the object is jiggled to separate it out of the background and rattled to make a sound to get Gannet’s attention. At 4 years old, Gannet finally identifies our faces as “mom” and “dad”. That was amazing. Big photographs are paired with the real objects to make connections, a first step for communication books.

**Hearing (Age 3-5):** It is clear that Gannet is a lover of sounds, and has a quicker reaction to auditory stimulus than vision. Certain sounds and music are experienced on a physical level, reverberating throughout his limbs. He begins to show preferences for different kinds of music: loves jazz, piano music, orchestras playing bold compositions like Stravinsky. He absolutely hates any kind of sing-songy music like nursery rhymes and Christmas carols especially sung by a soft female voice (they bring him to tears).

**Communication (Age 3-5):** At age 4, photographic communication books are created for home and school, and we're also taping photographs of objects on the actual objects everywhere. Visual training continues to the next level by introducing homemade picture books with photographs of common objects and people. The hope is that G will begin associating the pictures to the real things. It is the first step in abstract recognition and communication systems. G enjoys being read to, "glancing" at the pictures, and even turns the page with a crude swipe of his hand. We discuss the stories and try to get G to participate by pointing to details in the pictures. It seems like Gannet is making connections, although some people doubt this.

**Social and Behavior (Age 3-5):** Gannet is coming out of his shell. He is initiating more responses to different activities and engaging in rudimentary back and forth play (like tapping my hand if I offer it), and smiles spontaneously at life when he feels the urge.

**Learning and Teaching Styles and Sensory Integration (Age 3-5):** G is given hand-over-hand training, with verbal, visual and tactile cues for everything. Still going through the 3-stage prep before starting an activity or lesson.

**Health (Age 3-5):** The colostomy reversal is unsuccessful. G develops grand mal seizures (upon awakening from sleep) that are controlled by meds. MRI imaging reveals agenesis of the corpus callosum (the nerve fiber bundles that pass through and connect the entire left and half hemispheres of the brain). Perhaps that explains why it seems like G's reaction to sensory input - touch, sight, and hearing - seemed scrambled or non-existent and he frequently needs 10-15 seconds to process before responding. G takes a 2-hour nap every day after he's home from daycare

## Age 5-8



**Physical (Age 5-8):** Gannet is standing for a few moments by himself (but is nervous), and still too insecure to take a step without a hand or his walker for moral support. Physical therapists are still working on full range of motion. Orientation and Mobility therapy is introduced to help Gannet navigate through the world of obstacles at school and on the street.

**First steps: At age 8,** Gannet finally takes his first independent step for the school janitor on the playground. Jose has a big red truck, that Gannet is allowed to touch and tap every morning when he gets off the school bus. That makes them best of friends in the schoolyard. The entire school cheered for G that day!

**Fine Motor (Age 5-8):** Working on carrying objects (hand-over-hand) from one place to another. Emphasis is on carrying objects and eye-hand coordination like taking things apart and assembling them while focusing (not just the quick glance and averted gaze). True to form he laughs as he flings the objects away with complete abandon.

**Vision (Age 5-8):** G is now tracking objects and actively turns and watches things move across his field of vision. Peripheral vision is still dominant, but a straight-on focused connection is emerging. G definitely can see all and has excellent visual memory. By holding your hands for stability, he can guide you to exactly what he wants, wherever it is.

**Sensory Integration (Age 5-8):** The time delay between cause and effect is now 5 to 10 seconds for vision and hearing. A highly stimulating sound that he loves, like a motorcycle engine or bell, will overload his brain and Gannet will lose awareness of his body and might just fall over. Finding a balance between action and reaction, processing and overload takes a decade or more to overcome.





**Communication (Age 5-8):** Intelligence is confirmed. A more complex personality, intelligence, and a sense of humor is revealed. We make large communication boards with icons that represent everyday situations, people and objects and post them on the wall at home and at school. G begins to make intentional communication by pulling our hand towards a few of the icons more consistently (he will not point independently), recognizes his written name, and is actively leading us to places and people to communicate needs. He absolutely refuses to use “yes” and “no” icons, but we discovered he will “tactile sign” yes” and “no” by shaking our hand up and down in different combinations. I see a video about facilitated communication with autistic kids (while they type, they are dependent on a facilitator lightly touching their hand – or arm, but not guiding them in any way) and realize that although Gannet wasn’t typing, he responds to and depends on this “light touch” facilitated technique. We honor Gannet’s mix of expressive communication styles – leading us places, vocalizations, tactile signs, facilitated pointing to picture icons and words – and don’t ask him to conform to any one method (as the text books of the day say we should). The one communication style we do not put up with is his reliance on a tantrum to get his own way. Except for the tantrums, G does not initiate conversation, rather waits for someone else to approach him. G’s tolerance for having a conversation is limited to using 1-2 icons/words at a time, then he’s done, and upset if you try to get more out of him.

**Social and Behavior (Age 5-8):** Gannet is more social (in a parallel play kind of way), enjoys being around kids and his staff at school and daycare, and even begins to cooperate and initiate a bit. He participates in simple games (initiated by an adult) like pushing a truck across the floor and crawling after it. He loves it when the slightly older (non-handicapped) kids take on the role of mentor to play or read with him. G is incredibly stubborn if he doesn’t want to cooperate to a request to participate in a task. For example, I ask him to pick up his toothbrush and he refuses by whining, slapping and banging (one time I let him go for 45 minutes!) to get out of “work” instead of complying and being done in 2 minutes. Or, If he wants to go outside (and we aren’t ready) he will stage a hissy fit and bang his thumb and head on the window (now acrylic) for half an hour. That

never gets him anywhere, yet he persists. (It took years to “ignore” and redirect this behavior). Cooperation and negotiation skills did evolve over time.

**Learning and Teaching Styles (Age 5-8):** Gannet is inconsistent in responses from day to day (and still is). G’s 3<sup>rd</sup> grade teacher liked to test students. They needed to meet her criteria for a goal achieved, then (and only then) could they build on that and go to the next level. Gannet would still be at square one if all teachers were like her. It takes years of repetition and creativity before progress is observed, and inconsistency from day to day is part of Gannet’s life. At home and at school the teaching modality is to keep bombarding G with all kinds of sensory input, physical and intellectual stimulation to give him the benefit of the doubt that he is processing it all.

**Health (Age 5-8):**

Habit toilet training has begun, but diapers are still worn.

## Age 8-13



**A Turning Point and Higher expectations:** Mr. H, Gannet’s elementary and middle school teacher, ran a class best described as a cross between MTV and boot camp – he offered the most challenging, intense, amazing, stimulating, in-your-face yet respectful classroom strategy for the most severely handicapped and behaviorally challenged students in the school district. Nobody got to slide, and everybody had to raise the bar – staff, students and parents. Mr. H persevered to find chinks in his students’ armor, made contact and evoked amazing responses. Students were expected to take full responsibility for their success or failure...*and pay the consequences*. Mr.H was a radical professional and relentless - you either loved him or hated him. Gannet thrived in the excitement and intensity of this approach.

**Raising the bar for parenting:** To my surprise, Mr.H also tested my premise and beliefs about Gannet, and would get in my face – “so why is Gannet whining when expected to do something? Still in diapers? Can’t take off his coat? You’re still pushing him around in a stroller? And, one the day at a carnival Mr.H told me, “Mom, you don’t need a ticket for the Tilt-a-Whirl, because you son is going on the ride with his friends.” (my knuckles were white, but at least I negotiated that G sit in the middle, between his 2 slightly more coordinated schoolmates).

Gannet survived all the above, and his abilities grew in leaps and bounds - he never wore a diaper again in his life, hung up his coat and bag, could walk 4 miles every Friday, do simple word recognition and math tests, used his communication systems more consistently, and even managed to order a donut for himself now and then (by luck or intention).

*Raising the bar for higher expectations and letting go to allow Gannet to take full responsibility for his success or failure was an important (and scary) concept for me to embrace. It did us both good.*

**Physical: At age 9**, Gannet is still being pushed around in a stroller for long distances, and by **age 11** was walking 4 miles on the city hikes with his school mates. Although he still prefers to hold onto a hand or arm, he is expected to be in the lead and navigate to where he needs to be at any given time at school and at home. For example, if he's told it's dinnertime and he leads us to his truck in the living room, he's given a chance to correct. If he stays there he just might miss dinner that night.

**Fine Motor (Age 8-13):** Gannet is expected to initiate dressing and undressing, hang up his coat, and not toss it. He is learning to carry objects, to set them on a table, to operate a tape player for music, to turn on light switches and open doors, etc.

**Vision (Age 8-13):** Gannet uses his vision to locate and retrieve things. Still requires a "look" cue to stay focused.

**Sensory Integration (Age 8-13):** Still doing a lot of body prep before tabletop activities requiring fine motor and attention.

**Communication (Age 8-13):** G can point to and recognize pictures, icons and words familiar to his world using a book with over 300 icons – mostly nouns, like people, places and things, along with numbers, colors, defining concepts for choices, and feelings. The school bought Gannet a little communication device that had touch screen audio output. We could create multiple 12-icon Gannet stories that he could share with others.

**Social and Behavior: At age 9** Gannet, who would whine and bite his hands if asked to do something he didn't want to do, is put on the spot by Mr. H who exclaims "not in my classroom!" More to the point, a fellow classmate – a very large and strong kid – could not tolerate whining, and would make a flying tackle at the perpetrator if anybody as so much made a whimper. Peer pressure can influence behavior better than a teacher's rule.

**Learning and Teaching Styles (Age 8-13):** As explained, this is a most unusually animated, in-your-face, can do classroom that demands all staff be animated and expects full participation from all students – a cross between boot camp and MTV. It works. Gannet thrives and skills blossom. Mr. H also gives homework: Simple math questions using objects for numbers as well as dots; simple "spelling" games, like "find things that begin with the letter B." Gannet enjoys homework, and shows pride in his accomplishments. It's nice to have him point to feeling "proud" instead of icons for "crazy" and "confused."

**Health (Age 8-13):** From the first day of class with Mr. H, Gannet never wears a diaper again. The staff uses habit training and keeps him on a tight schedule, and slowly extended the times between. G doesn't spontaneously ask to go to the restroom, nor would he lead you there. Returning home from the after-school program, he takes a 2 hour nap before dinner.

## Age 14-22 – High School Years



Gannet is emotionally ready for high school, and really enjoys the new scene and status.

**Classroom vs Integration:** G has minimal options for integration with the regular students (the lunchroom being one, the hallways, and piano lab), but between his classroom and the community program, it is a stimulating program. He still has a 1:1 aide, and receives all the specialized services – vision, orientation mobility, speech, physical and occupational therapy – as well as classroom instruction and community training. He also attends an afterschool rec program for teens with disabilities that includes swimming, gym, art, field trips...

**Physical (Age 14-22):** He shuffles slowly when walking, and one goal is to pick up the pace and walk independently from place to place. He's very cautious about falling and uneven surfaces, so people name hazards and try to get him to "look" while navigating indoors and out to prepare himself, not rely on others.

**Fine Motor and Vocational Training (Age 14-22):** Gannet's job in the community is detailing used motorcycles at a local shop. He needs to hold and grasp a spray bottle and squeeze it to wet down the surface, as well as hold onto a rag and move it back and forth to clean. Both tasks are difficult for G. He eventually gains enough fine control to accomplish independent squirts (before flinging the bottle), and a few swipes with the rag (before tossing it in the air). At home he also holds the hose and shakes it to rinse my car. Another job is recycling school trash at a big center. Gannet loves the sound of crashing glass, and is thrilled to have a job that includes flinging bottles.

**Sensory Integration and teaching techniques(Age 14-22):** The teacher and therapists began working together and cross-pollinating their services with each other's expertise. They put together some really creative activities for intellectual, physical and sensory stimulation. For example, the speech therapist would read web and newspaper articles – from science to current affairs and highlight certain

words and concepts with G, and G was expected to discuss them while his OT was assisting him with the communication device and helping him navigate the web to pursue answers and more info if interested. They also made icon recipe books for cooking experiments – reading and follow-through.

**Augmented Communication Device:(Age 14-22):** The school gave G an augmented communication device (which was too heavy to travel with him), and he continued to use small paper icon books in the community and at home.

**Health:** Good. G is knock-knee'd and his kneecap slipped out twice, and he was braced for months until it was healed. The 2 hour after nap before dinner is an institution.

**Vocational training (Age 14-22):** A local motorcycle shop adopted him and set him up detailing their used motorcycle line. G can barely keep the rag and spritz bottle in his hand, but the kid loves motorcycle and it is heaven. He is expected to socialize with the guys in the shop, and also learn the names of all the key parts.

**A typical teen:** Gannet has to negotiate a faster pace of life, with school hallways filled with action and drama. He learns to pick up the pace, and walk a straighter line. And like a typical teen, to hold his head up and “look cool” when he wants to impress certain students in the hall or on the street after school. At home, Gannet is showing signs typical of a teenager pulling away. When we go out to a coffee shop, he sits down and turns his back on me, like “I’m not with her.” He’s much more into what he wants to do, not compliant to just go out on errands with me, or eat at the restaurant I choose when he has another in mind.

**Social & emotional skills(Age 14-22):** Tantrums and head butts, along with self-abusive face slapping are still Gannet’s emotional response to frustration, to stop an activity, or to express being tired. We model deep breathing exercises to divert the negative energy, and G learns to respond. G likes being around his friends, but sustained social contact is rare – the same idea as parallel play. He walks up and greets adults and friends by placing his hand on their shoulder. He gives family a great hug.

**Extreme Behavior(Age 14-22):** There are times when in the middle of a good mood, something comes over him (like a hot flash) and he freaks and starts biting his hands and banging his head violently against any hard surface. This is getting more severe as he gets older, and we’ve got behavior modification and deep breathing relaxation protocols to follow. Usually successful, but unpredictable.

**Fine Motor Skills (Age 14-22):** He can hold an object for many seconds and is expected to carry it to a location...but is likely to drop it before getting there. He refuses to hold a pen or pencil, and the school staff help him write words, hand-over-hand. G follows simple directions, and sometimes can do a step or two independently. One thing is clear, that G has good days when he is capable, and

bad days when he drags and things just don't go well. You never know what kind of day to expect.

**Advice from Mom to son:** *At this time I started giving G a reality check about the adult world, primarily that the world is NOT your oyster, and I will not be there. The more skills you can build and the more you are willing to participate and cooperate with teachers and staff, the better your life will be. If you sit back and be a passenger, you will be treated like an invalid, stuck in a corner to suck on your hands and bang your head all day...life will be miserable. It's your call to succeed or fail.*

Gannet graduated high school at age 22.

## Age 23-24



**Gannet is so ready to move out** into Supported Living but also communicates that he is “scared” and “anxious.” He has a ready-made team of staff, some who have worked with him for years in high school and others who were their friends. This is a time of transition for Gannet and I would say his development and skills plateau for quite a while. *(This is a time of rude awakening for me, as adult agencies and services are nothing like the public school system.)* Gannet is thriving with his new “family,” and is living the life of a hipster in SF’s Mission District. A documentary movie of his life, “The Key of G,” features the relationships between caregivers and Gannet as G moved out of my house into his own apartment. The trailer and more info and photos are at <http://www.lateralfilms/keyofg>.

**Missed Communication, Cataracts and recovery:** 2 years prior Gannet had been holding his hand to his eyes and forehead, and pointing to the corresponding icons for “headache”, and “forehead,” “crazy” and “pain.” We all responded to him with “Oh, you have headache, here’s 2 aspirin.” We totally missed the boat. Gannet was actually developing cataracts in both eyes, which wasn’t discovered until he was already blind in one eye, with failing vision in the other. This is devastating to him, and he becomes very angry, withdrawn and fearful. The surgeons were not going to replace the lenses if Gannet’s habit of banging his head into walls, and hitting his eyes could not be curbed. For another year we use arm braces and behavior modification along with straight talk, to help Gannet curb self-abusive behavior. The surgeons agree to operate. G’s vision and personality bounce back. As a side benefit, Gannet is a lot more mature and cooperative with all his doctor visits and in general. Something clicks, another milestone is achieved.

**Welcome to Mowat-Wilson Syndrome and more:** The Mowat-Wilson diagnosis at age 24 doesn't change a thing...except it is fascinating to know that he belongs to a tribe of similar people who look like him, and shares other traits and characteristics.

**Health (Age 22-24):** Frequent frontal lobe seizures take hold, and are now mostly controlled with meds. Gannet get's colds that knock him out for weeks. Takes his daily nap.

## From 20's - 30's and beyond



**New Milestones keep on coming:** Abilities that I'd entirely wrote off by age 10, like taking himself to the toilet - actually became reality in his late 20's, as did many other skills like being more independent setting the table, getting food out of the fridge, adding complexity to sentences and thoughts, composing and recording music. Gannet is much more mature, follows simple directions, and is more cooperative. He understands process when explained, and can be patient. Gannet is proof that you should never let anybody set limits or lose hope.

*Now that we've arrived at the current place in time in Gannet's adult life, I feel like I'm invading his privacy if I disclose really personal information.*



**Daily life as an adult:** At this time, Gannet has many dedicated staff who work with him 24/7, and assist him to live a full and productive life. He continues to be in a program called Supported Living and lives in his own apartment with a staff person, who is also his household manager. G has a weekday program from 9-3 with a mix of leisure and vocational activities. He is asked to make choices, and has control over most aspects in his daily life, and receives 1:1 facilitation for key parts of all self-help skills and daily activities. Gannet makes friends with adults who are more adept at sustaining interests and conversation. G has a harder

time sustaining long social activities with peers, but does show interest in being with his friends.

**Communication systems (Age 20-30s):** An iPad with the app ProLoQuo is the new icon based voice-output communication system. G's use of this can be direct and clear, but the message can also be cryptic. He has more patience to keep at it if not understood. The iPad has many other apps for communication and music. An extensive collection of photos serves as Gannet's memory, and he loves to share those memories with friends and family.

**Self Help Skills (Age 20-30s):** Needs varying levels of prompts and assistance in most self help skills, and participates to complete tasks to the best of his ability.

**Household jobs: (Age 20-30s):** Helps with dinner – picks the menu, goes shopping, pulls out ingredients and sets the table. Waters the garden and pulls weeds. Pulls clothes out of the laundry, and puts his folded clothes in the right drawer (or flings them in the air). Washes the car by holding the hose to rinse, and helps with the spritzer bottle and rag for windows.

**Leisure at Home (Age 20-30s):** Loves to play his keyboards, and has a sophisticated system for laying down tracks to record. Has friends over to jam. Watches little TV. Listens to music. Likes to be read to – interesting articles in magazines with follow-up web searches using a touch screen. The old yellow truck chassis with big wheels sits in the corner, and once in a while he gets the wheels spinning as a calm-me-down lost in his own zone. Takes a nap everyday from 3:30 to 5:30.

**Out on the town (Age 20-30s):** G makes choices for what he wants to do, and where he wants to go. Gannet gets around the city by walking and by bus and loves to go out to local parks, swimming pools, the beach, hiking, to movies and museums. He participates in shopping for food at the neighborhood supermarket and farmer's market. At night he goes to movies or local clubs to hear music (before it gets too crowded). He likes adventures out of town day & overnights.

**Day program activities:** Activities include cooking class (from shopping for the food to cleanup), music therapy classes, meeting peers at the gym and bowling alley, swimming, detailing antique cars at a local museum, going to movies and other entertainment, field trips to museums, etc.

## He's a pretty lovable guy...

Gannet's had this charm about him throughout his entire life. He has been able to inspire people working with him to believe in his potential, to be creative. They've had the patience to not give up, rather keep at it allowing him to grow intellectually and physically one small step at a time. Gannet is a crazy combination of opposites, he is severely disabled and he is a complete and interesting human being. Sometimes his behavior seems to indicate he could care less, then he rattles off a long conversation (using icons) about how



passionate he feels. Gannet is a conundrum; his inconsistency is one of the most consistent characteristics. And for all that he's a pretty likeable, lovable guy.

**A tribute to competent, caring, professional staff:** Gannet's life is only as good as the people who support him and believe that he is a whole person. I need to pay tribute to Alex Gallego, G's current primary staff and household coordinator, who has had the patience to be Gannet's adult mentor, as well as a good friend who respects him as a capable person and keeps raising the bar.

To see more photos of Gannet's life today: [www.gannetsnotes.com](http://www.gannetsnotes.com)

**A documentary about Gannet:**



**THE KEY OF G** is an award-winning feature documentary about disability, caregiving and interdependence. The film follows Gannet, a charismatic 22-year-old with physical and developmental disabilities, as he leaves his mother's home to share an apartment with a close-knit group of artists and musicians who support him, not only as paid caregivers, but also as friends. Together they create a uniquely successful model of supported living, and a compelling alternative to institutionalized care.

**LINK to Key of G:** [www.lateralfilms.com/keyofg](http://www.lateralfilms.com/keyofg)