

FINDING Your Passion

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CERTAIN PEOPLE COME INTO YOUR LIFE AND

they make you re-evaluate your priorities: am I fulfilled with what I am doing, am I making an impact on people's lives around me, what is my next big challenge? Laura's case caused me to question all of these things and with the team that I work with, I know we helped Laura answer some of these for herself.

Laura was referred to our clinic in the spring of 2010. She had been a repeat patient of our clinic over the years due to pain and post surgical loss of function. She has neurofibromatosis causing tumors to grow in her central and peripheral nervous system. To preserve function and decrease pain she has undergone multiple cervical and lumbar laminectomies. She developed scoliosis due to lack of muscular stability post surgery. She underwent a hemipelvectomy on the right five years prior. She has dependent edema of left distal leg. Surgical transfers of bilateral ulnar nerves, a left arm tendon transfer of ECRL and FPL, along with a left median nerve dissection result in decreased grip and limited flexibility at elbow and wrist. She has dealt with ischial and coccygeal wounds post surgeries and upon referral had a stage I coccyx sore. She has chronic neck, back and worsening complaint of shoulder pain over the past year. Tumors present on her head caused hypersensitivity to touch at the back of her skull.

Laura is a neurologist but had to discontinue practicing due to advancing medical difficulties. She had used a rear wheel drive power chair due to weakness after cervical and lumbar surgeries for multiple years but had transitioned to a manual Quickie Titanium for ease with transportation — driving with roof chair lift on a sedan with hand controls. She reported discomfort with sitting ever since the hemipelvectomy and had moved from

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"THE CUSHION CHANGED MY LIFE. I CAN NOW SIT FOR LONG PERIODS OF TIME WITH COMFORT. IT HAS GIVEN MY LIFE BACK TO ME," SAID LAURA.

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use of a 2-valve Roho to a Roho Quatro high profile. She reported feeling like she was sitting on a "golf ball" at her coccyx. Balance within the seating system with mild dump and an adjustable tension back support was also an issue. She had found that by inflating the right half of her Roho to accommodate her obliquity assisted with stability but further compromised her comfort at her tailbone. Her propulsion ability had declined in the past year from one mile in fall 2009 to 10 minutes in spring 2010. Pain also limited her sitting tolerance to 10-15 minutes. Laura stated that her life had become very "narrow" with limited community access and even for completion of self care. She was able to live independently but had to increase reliance on family and friends for assist with cleaning her home and grocery shopping.

The Assistive Technology Clinic that I work at relies on the expertise of the treating therapist, patient-chosen vendor and rehab engineering. I definitely benefited, as did Laura, with this team collaboration. During the next eight months, the team would work closely with Laura challenging us to meet her changing needs along the way — surgery for more tumor removals, joint pain at shoulders and left leg, and skin breakdown. We utilized objective measures to assist with documentation for funding sources and decision making for equipment. The Smart Wheel, pressure mapping, plus Kirby's skills checklist with manual and power wheelchair propulsion were used as well for modifications as needed to the equipment. Orthopedic treatment with physical and occupational therapy also assisted in her achieving optimal functional ability with self care, transfers and propulsion as recommended by the treating therapist in the team.

The initial plan for equipment took into account her presentation with a wound and inability to pressure relief effectively or frequently (postural asymmetry and extremity/trunk weakness), shoulder pain, plus she was an ineffective propeller. The Smart Wheel demonstrated that she was a successful propeller for short distances but with increased arm strain to complete. Long distance propulsion in community was limited with asymmetric arm strength and ROM. The Smart Wheel numbers in comparison to norms demonstrated her as an unsuccessful propeller out of the home — via stroke length and force production. Pain and inability for community propulsion had her pursuing power mobility. We completed a trial mold for back and cushion support



TOP: ORIGINAL WHEELCHAIR WITH AIR CUSHION AND SLING BACK. EQUIPMENT DID NOT PROVIDE ANY STABILITY AND CAUSED POOR SITTING TOLERANCE WITH SIGNIFICANT PAIN.

BOTTOM: FINAL SEATING SYSTEM WITH CUSTOM CONTOURED CUSHION AND CUSTOM CONTOURED BACK. SEATING SYSTEM ALLOWS BALANCE, ADEQUATE PRESSURE DISTRIBUTION AND INCREASED COMFORT. SPECIAL MOLDING OF THE BACK ALLOWED TRUNK STABILITY THAT HAS NEVER BEEN ACHIEVED IN ANY OTHER SEATING SYSTEM AND PERMITS SUFFICIENT ACCESS TO THE WHEELS FOR INDEPENDENT MANUAL WHEELCHAIR PROPULSION.

to determine client's tolerance to and effect on pain. She was excited and wanted to pursue. The vendor was most familiar with a specific type of molding process and implementation. The client's preference for type of molding system changed when we invited her as a case study at a training program at our facility for this manufacturer. She was so pleased with the feel — the "golf ball" was gone" that as a group we decided to pursue this molding system for her power wheelchair. Laura still required the manual wheelchair for independent driving with her roof chair lift and requested ordering a new manual wheelchair with the same lightweight custom seating for back and cushion. She was fortunate to be able to self fund the manual wheelchair for community and insurance funding for the power wheelchair for use at home and outdoor in area of her home.

Multiple fittings and "tweaking" for both power and manual wheelchair seating systems were completed per client request and with one month follow ups to determine independence and efficiency with mobility, transfers, pressure relief, and self care (reach, balance, etc.). The results for Laura exceeded her initial goals for pressure relief and increased sitting tolerance. She had the energy and ambition to pursue a new dream: kayaking. Utilizing her cushion she was able to kayak class II and III rapids in the Smoky Mountains with First Descents. This organization provides adventure opportunities outdoors for cancer survivors. In a phone conversation with Laura, she told me that she had an "addiction to kayaking ... the high lasts for months." She is planning kayaking tours in other national parks and in a river with a dam close to home.

Laura's case was unique for the fact that she was able to secure two seating systems to assist her within home and community with the fluctuating needs that she has depending on tumor growth/location and surgery recovery. But, our team staying persistent with trial of equipment to secure appropriate pieces and appropriate measures to justify the need for each incremental change in fitting, can be carried over into every case. The end result for Laura is her ability to pursue a passion that a year prior she had never thought possible and on a personal level for me, reaffirm my passion in what I get to do each day with my team. ➡

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