

# Providing POWER MOBILITY for a Child with SMA I

Written By Michelle L. Lange, OTR, ABDA, ATP/SMS

## JACK IS AN 8-YEAR-OLD BOY WITH THE

diagnosis of Spinal Muscular Atrophy, type I. He has been vent dependent for most of his young life and has extremely little active movement. If he is going to be functional in any area of life – mobility, communication, education, or play – it is going to involve assistive technology.

## WHO IS JACK?

Jack lives with his parents and younger brother, Dylan. He likes to watch Nickelodeon on television and tends to get annoyed with Dylan for being so hyper. In these ways, he is very much like many 8-year-old boys, but the similarities soon cease. He spends almost all of his time in a hospital bed in the family room. This room is large enough to hold all of his medical equipment and is on the main level of the home. His mom can keep a better eye on him as she takes care of things at home. He doesn't go to school and is rarely in his wheelchair. He has no functional communication or control. He is probably used to it, but I think he gets really bored, even with a big screen TV in the room.

## WHAT INTERVENTIONS HAVE ALREADY BEEN TRIED?

Fast forward a bit. Jack doesn't go to school for a number of reasons, but he does have teachers from the school come to his home. One of those teachers had someone from the assistive technology team come along one day to meet Jack. The AT person proceeded to try some switches to provide access to a speech generating device so Jack could communicate with those around him. The team continued to try various switches for two years, but with no success. Jack did, however, get a speech generating device (SGD) and was starting to use it.

quickly with this facilitated access so Jack was eventually referred to a private speech language pathologist specializing in augmentative communication.

## EVALUATION:

This SLP happens to work with me a lot, so she called and asked if I would see Jack to evaluate him for independent switch access so she could proceed with the SGD, positioning (as he wasn't getting in the manual wheelchair for a reason) and mobility (as he had none). So I took a drive and met Jack and his mom. After talking a bit about Jack, his current equipment, what worked, what hadn't worked and their goals, I started evaluating his active movement and force.

## SWITCH ACCESS:

Jack could lift his forefinger and thumb together on each hand with very little force. He had no other volitional movement while supine in bed. I thought I knew of a switch that would work for him, but I didn't happen to have that one in my trunk. I told his mom I would borrow one from the manufacturer (Adaptive Switch Labs) and come back. She wasn't convinced. After all, she had watched people come and go with numerous switches during two years time with no success. I told her I understood her reservations, but I really thought this might work. She said I could come back, and so I did a few weeks later with my borrowed fiberoptic switch and power supply. Fiberoptic switches are great at capturing very small movements and require no force. Also, they can be set up in a "normally closed" position. Most switches are "normally open" and must be "closed" or pressed to be activated. In this case, Jack could rest a finger over the top of this fiberoptic switch and lift off of it to activate.

By resting on the switch, Jack's muscles did not fatigue by hovering over the switch itself. Fiberoptic switches (*see picture*) emit a fiberoptic light and when that light is reflected back by something, like a finger, the switch is activated. The switch was plugged into the SGD and Jack began scanning independently and quickly. So why hadn't all those other switches worked? They were mechanical switches and required force to depress the switch surface. Jack didn't have that force due to profound muscle weakness. Fiberoptic switches are electrical switches. No force is required, but a power source is. A wheelchair armtrough (*custom fabricated by Aspen Seating*) was placed in the bed with the switch mounted under his left index finger. This maintained his alignment with the switch for access and mounted the switch.



ASL FIBEROPTIC SWITCH UNDER  
JACK'S INDEX FINGER

How? Well, a miniature drumstick was taped to his right index finger and his hand was placed on a tambourine. When Jack wanted to make a selection on the SGD, he could tap the drumstick on the tambourine. A facilitator would then press a switch for him. He still wasn't progressing very

## POSITIONING:

Jack was positioned well in bed and had no redness or history of pressure sores. His family was taking very good care of his skin. Jack was not spending much time in his wheelchair, so I asked his mom what was going on. He had a Quickie tilt-in-space manual wheelchair with a custom molded Aspen Seating Orthosis seating system. He required this level of support to hold his body upright due to profound muscle weakness and atrophy. Jack wasn't tolerating the seating system very well as he was sitting up too tall in it. He needed to recline more to be more comfortable. Even though the tilt helped reduce the effects of gravity on his body, he needed a more open seat-to-back angle.

Sitting upright was possible with this level of support, but not always comfortable. The seating system was eventually modified to include a partial recline and a manual recline was added to the wheelchair. Another reason Jack didn't like his wheelchair was that he couldn't do anything in it. A fiberoptic switch was mounted in the left arm trough so he could use the SGD from the manual wheelchair. When he was upright, the angle of his wrist had to be very specific (in slight flexion) to optimize switch access, so a custom arm trough was built. He also had a tendency to deviate laterally, so a wall was built on the armtrough to maintain a neutral wrist position.

## MOBILITY:

Finding one switch site was a challenge. Driving a power wheelchair with one switch is possible, but can be very inefficient. I needed to find three more switch sites if I could. With four total switch sites, we could cover forward, left, right and reset. The first three would give Jack movement in a power wheelchair. Reset redefines what the other three switches could do including reverse, speed, tilt and accessing the speech generating device from one of the power wheelchair drive switches. I was excited to get Jack driving, and I was hoping he would love it. This little guy had hardly left his bed except for medical appointments, and I was betting he wanted some control over his life ... Now Jack had movement of the forefinger and thumb on his right hand as well, so we could put a fiberoptic switch there.

Remember "normally closed?" Well, that won't work for driving as this could place the driver in an unsafe situation. If Jack couldn't get his finger over the switch, the chair wouldn't stop. We had to use "normally open." Hovering over the switch that long was too hard. We placed the fiberoptic switches in the end of the arm trough, facing directly forward instead of facing upward (see picture). His fingers hung over the edge of the arm trough, and he pulled his finger back toward the fiberoptic to activate. This allowed him to rest his fingers when he wasn't driving.

Two down, two to go. Once Jack was upright in his manual wheelchair, he could adduct his legs slightly and could do so even better if his feet were raised just a bit to allow gravity to assist. Now, we needed some switches to capture this movement at the medial knees without requiring force. For this situation, I chose proximity



ASL PROXIMITY SWITCHES BY MEDIAL KNEES



ASPEN SEATING CUSTOM ARM TROUGH

switches. Proximity switches are larger than fiberoptics and were more appropriate to capture this larger movement. He only needed to approach the target to activate it, and we could adjust the activation range. The fiberoptic under his left forefinger controlled forward, the fiberoptic under his right forefinger controlled right, the proximity switch by the left medial knee controlled left and the proximity switch by the right medial knee is reset.

Ordering a power wheelchair to support these switches, control a power tilt through the drive control and interface the SGD required a lot of documentation for successful funding and a very, very long fitting (thanks to Kevin at ATG Rehab in Colorado Springs and Keith of Aspen Seating), but it was so worth it! To watch Jack chase his little brother down the street was priceless. Jack has full directional control of his power wheelchair, can access reverse, can control his power tilt and control his SGD through the switch under his left forefinger.

## COMPUTER:

I love high-end speech generating devices — they are so powerful! The SGD can send wireless signals to a computer for efficient text entry. Jack scans through vocabulary options on his SGD, builds sentences and sends these to a word processing program on his computer. This, and the speech output, has allowed him to demonstrate his learning for school. He also uses keyboard shortcuts for common commands such as Save and Print.

## CONTROL:

Those SGDs can also send infrared (IR) signals to control devices in the environment — cool! Jack uses his SGD to control the big screen TV in the family room, as well as the DVD player. This makes watching TV a lot less boring and gives him a chance to change the channel when Dylan tries to watch Dora! After all, that is a big brother's job.

When working with a client like Jack, it is so easy to focus on all the things he can't do as a result of SMA. That's why I love assistive technology. It allows clients like Jack to be kids who can move, communicate and even change the channel on the TV to annoy their little brother. ▶

## CONTACT THE AUTHOR

Michele may be reached at [michellelange@msn.com](mailto:michellelange@msn.com) or 720.333.2661.