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THE PREVALENCE AND IMPACT OF PAIN ASSOCIATED WITH UPPER-LIMB AMPUTATION P34

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Cutting-edge information for the prosthetics, orthotics, pedorthics, and allied healthcare professions.

GOINGCYBORG

Advanced Prosthetic Technologies Take the Spotlight

By Sherri Edge

hen Rebekah Marine glided down the runway as part of New York Fashion Week in February 2015, she wore a short, slinky dress, silver body paint, and a right arm that was clearly a high-tech prosthesis. She wasn't the only model that day who looked unexpectedly different. There were women rolling out in wheelchairs,

a young man walking on a carbon fiber prosthetic leg, and a teenage girl with Down syndrome. It was a revolutionary moment in the world of high fashion, a domain that traditionally views beauty through the lens of physical perfection.

Sharif Dakhan appreciates the "cool factor" of his bebionic hand. *Photographs courtesy of Advanced Arm Dynamics*.

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Marine credits her i-limb hand with boosting her modeling career. Photograph courtesy of Steven Woods/Csaw Studios.

"I think it's so cool to just kind of be at the front of the line of this change. Being able to inspire others to open the doors and open their minds to different models—it's a humbling experience," Marine told *Time* magazine ("Meet the Bionic Model Who Walked in New York Fashion Week," by Anne Most, September 16, 2015).

That day on the runway reflected a wider social trend where individuality, creative expression, and standing out from the crowd is encouraged and celebrated. It also fits with a shift that's occurring in upper-limb prostheses, where lifelike cosmeses are being eclipsed by arms and hands that look distinctly bionic. For some prosthesis users, the goal of blending in isn't nearly as appealing as standing out with a hand that looks like it came out of *Star Wars* or *I, Robot.*

Marine was born with a partial right arm. Her first prosthesis was a bodypowered hook that she struggled with using, and around third grade she stopped wearing it completely. With the support of her family and acceptance of her friends, she says that growing up with a limb difference was not particularly challenging. In fact, it was during those years she began dreaming about what it would be like to become a model.

"When I was a kid, I always fit in with my friends," she says. "I grew up with the same kids from kindergarten until the day I graduated high school, so it was after I left high school when I began to realize I was different." In college, she was surrounded by new people who didn't know her story or understand her capabilities.

I like celebrating the cyborg look because I don't care that people know I have one hand. I don't need to look like everybody else with two hands. I can look like myself and I get to wear this amazing device that helps me do really cool things in my life.

– Angel Giuffria

Marine was in her early 20s when she got serious about modeling and decided to try a myoelectric hand with a cosmetic glove that matched her skin tone. She was frustrated by the lack of a precision grip, and before long, she was researching the newest multiarticulating hands and making friends with people who use them. She found Advanced Arm Dynamics' Northeast Center of Excellence, Philadelphia, scheduled an evaluation, and now uses a Touch Bionics i-limb[™] quantum hand.

For Marine, her new bionic hand is a double win. She says the technology made her day-to-day life easier, enabling her to use both hands to type on a keyboard, carry her groceries, and get her laundry hamper down stairs. But it's the appearance of the hand that she truly embraces. She describes it as really futuristic looking and identifies herself as the Bionic Model.

"Having the prosthetic hand has made a world of difference because people notice me now, people recognize me," Marine told mashable.com ("Meet the Runway Model Who was Born Without a Right Forearm," by Mark Andrew Boyer, November 10, 2015).

Since her New York runway debut in 2015, Marine has modeled in Fashion Week four times, appeared in the 2015 Nordstrom catalog, and been featured in an ad campaign for Frameri eyewear. She is also an inspirational speaker and an ambassador for the Lucky Fins Project, a nonprofit organization that supports those with upperlimb differences. €

A Visible Difference

arine's story is just one example of a subtle cultural shift: The visibility of people with limb absence and people who wear prostheses has increased significantly over the past ten years. This shift coincides with the introduction of advanced prosthetic hands and other sophisticated components that look like something out of a science fiction movie. On a national level, extensive media stories about injured service members returning from the wars in Iraq and Afghanistan have helped increase awareness of limb loss and prosthesis use.

"The number of people

who have actually seen a high-tech prosthesis has probably risen exponentially," says Julian Wells, CPO, clinical manager, Advanced Arm Dynamics' Midwest Center of Excellence, Kansas City, Kansas. "That exposure, even though it may be on a very rudimentary level, has created more of a normalizing awareness. It's a real contrast to just hearing about advanced prostheses but never actually seeing them."

Historically, advances in prosthetic technologies have followed armed conflicts, where limb loss is commonplace. For upper-limb prostheses, the most dramatic increase in funding

for research and development occurred in 2006 when the Defense Advanced Research Project Agency (DARPA) launched the **Revolutionizing Prosthetics** program. This U.S. Department of Defense initiative, a direct response to the increase in upper-limb loss due to blast injuries, had the goal of jump-starting the production of an advanced, neurally controlled upperlimb prosthesis. To that end, \$18.1 million was awarded to DEKA Research and Development, Manchester, New Hampshire, in 2007, and in 2009, \$30.4 million was awarded to the Johns Hopkins University Applied Physics Laboratory ("DARPA Prosthetics

Programs Seek Natural Upper Limb," by David Pope, Neurotech Business *Report*). At the same time, private prosthetics manufacturers like Ottobock, Touch Bionics, RSLSteeper, Motion Control, APS, Infinite Biomedical Technologies, and others were already engaged in developing technology for advanced prosthetic hands. The first multiarticulating hand became available in 2007 with the release of the original Touch Bionics i-limb hand. RSLSteeper's bebionic hand was introduced in 2010; in 2011, Ottobock's Michelangelo hand became available, first to American service members, and in 2012, to civilians. 😔



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Like many prosthetists, upper-limb specialist Rob Dodson, CPO/L, FAAOP, clinical manager, Advanced Arm Dynamics' Southwest Center of Excellence, Dallas, says he is excited to be part of the technology revolution in prosthetic hands.

"Just nine years ago, the types of upper-limb components that patients had to choose from were all very similar," he says. "They had one grip pattern-the three-jaw chuck-and a hand shell that looked similar to a human hand. with a cover that was skin tone of some sort. Those were the options. What the newer hand systems provide is more natural shaping of the hand, particularly the fingers. It's more malleable. They can lay flat, make a fist, point with one finger, do a thumbs up, or [do] a lateral key grasp. The effect of a cool device is people wear it more and don't want to hide it underneath a skin tone silicone glove."

However, it's worth noting that the bionic look is not for everyone. "Some people don't want to be flashy and exposed to the world. They don't want to answer everyone's questions about 'How does that work?" Dodson says. "There are definitely men

and women who really want their prosthesis to look as close to a normal limb as possible."



Giuffria shows off her "storm trooper" hand.

From Basic Hand to Bold Tech

ngel Giuffria is an eyewitness to the technological evolution of upper-limb prosthetics. Born in the 1990s with a partial hand, she was fitted with a passive hand at six weeks of age, and a myoelectric arm at four months. Giuffria's mother was an advocate of prosthetic use, even though the idea of fitting babies and young children was something new.

"Insurance companies really don't want to fit children that much because they grow so fast and don't see the use in it," Giuffria says. "But I used my arm all the time, from hitting my mobile to picking up toys and even pinching my brother when I got old enough to realize I could do that."

She believes that from the

beginning, her prosthetic arm was an important part of who she is and that it gives her a lot of confidence. On the lighter side, she's always had fun playing pranks with her prosthesis, and found it especially "handy" for working as a zombie in a haunted house. She got involved in community theater as a child, performed in high school plays, and continued with acting and modeling during college and beyond.

In 2013, Giuffria heard about an opportunity to be a test patient for the DARPA-funded DEKA arm and she jumped at the chance. She experienced a breakthrough using the DEKA arm: The rotation and flexion of the wrist allowed her to bring food to her mouth for the first time with a prosthesis. "I was like, 'I can touch my mouth!' I remember the first day I did it—I was so excited," she told *The Lion's Roar* ("Graduate Student Tests DEKA Arm Prototype," by Melanie Mann, September 17, 2013).

Not long after that experience. Giuffria decided to consult with a clinician who is an upper-limb prosthetics specialist. After many years of wearing a standard myoelectric hand with one grip pattern, she made the technological leap to a bebionic hand that had a glossy white and black finish and a carbon fiber socket. As a petite woman, she was thrilled to be among the first to receive the bebionic small, sized specifically for people of smaller stature. ♦



Kinney says his i-limb hands have given him a more positive outlook about having bilateral amputations.

"When I was little, I didn't really have a choice. Everybody immediately went for the flesh-colored glove," she says. "And the idea was, we didn't want people to know that we had one hand. But it was like we didn't want them to know because having one hand was bad.

"And it...became, 'Why is it bad?' For me, I was born without my hand. That's me," Giuffria says.

"So I like celebrating the cyborg look because I don't care that people know I have one hand. I don't need to look like everybody else with two hands. I can look like myself and I get to wear this amazing device that helps me do really cool things in my life."

Currently, Giuffria works as an actress and has done background work in several major motion pictures, including *Green Lantern*, The Hunger Games: Mockingjay-Part 1, and The Accountant. She is also a speaker who enjoys talking about wearable technology and what it means to be a cyborg, and is a mentor and camp counselor for children with limb differences and limb loss. She is about to complete her graduate degree in psychology; her thesis examines the social stigma and attitudes faced by people with limb loss.

The New Bionic Men

eople with lower-limb amputations, particularly men, were the first to embrace the mechanical appearance of prostheses sans cosmetic coverings. That was in the mid-1990s. With the introduction of the first multiarticulating hand in 2007, a similar trend began to unfold among upper-limb prosthesis users.

Wells points out that with the exception of the bebionic hand, component manufacturers still prefer that prosthetic hands have a silicone glove for protection from moisture and dust. "Black gloves and clear gloves actually go along with that vision of the cyborg," he says, "and clear gloves let you see a glimpse of the inner workings of the hand."

Sharif Dakhan and Gerry Kinney are two examples of men with upper-limb amputations who want to wear prostheses that look bionic. Dakhan underwent an elbow disarticulation in 2013 when he was 22 years old; he describes his carbon fiber arm and bebionic hand as eye-catching and very functional. Kinney, who had worked as a lineman for 17 years, lost both his arms below the elbow in July 2015 when he accidently brushed across a power line and was electrocuted. Today he wears two i-limb quantum hands with clear gloves most of the time, and also has electric hooks for working in the garage and on vehicles, and durable, body-powered hooks he can switch to for chores such as trimming hedges or mowing the lawn.

When Dakhan was being fit for a prosthesis, he wanted to wear a device that looked like it was from the future. "I don't have a left forearm or hand anymore. I wear a prosthesis. So why try to make it look like something it's not?" he says. "A prosthesis like mine kind of invites people to ask about it and I love talking about it. When I tell the story of how this happened, and how lucky I was to get this technology, people really take it to heart. And sometimes they bring out a story of what happened to them or to someone they know. The conversation gets personal a lot more quickly."

Kinney has had similar experiences. The futuristic look of his prostheses attracts a lot of attention and he frequently gets into long conversations with total strangers. "When my arms were being built, they asked if I wanted my prostheses to match the skin tone on my upper arms and I said, 'I've seen that carbon fiber and it looks pretty cool," Kinney says. "And I can't tell you how many people you walk up to and they go, 'Oh cool, carbon fiber!'" €

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Dakhan met his wife, Nicole, about a year after he began wearing a prosthesis. He admits that he was nervous about starting to date again and thought he might never have a relationship. "It's something every person who loses an arm wonders about," he says. They met on the job, and Nicole said that part of her initial attraction was his bionic arm. While working at a trade show together, she noticed him struggling with placing stickers on brochures so she offered to help. "I wasn't really struggling. I just wanted her to come help me," he says.

Kinney's wife, Denice, has been beside him through the entire process of hospitalization, amputations, and prosthetic fittings. "Once we got to an upper-limb specialist and were able to see what the future held for him in prosthetic technology, it was very overwhelming and emotional to me," she says.

"You can't even explain how much it's changed your life," Kinney says. "Just being able to go out and walk around, you almost feel normal again. You reach out and you can actually grab something. These hands have five grip patterns programmed in, and I can get dozens of other grips with an iPod."

Identity Reboot

hether they see themselves as high-tech, bionic, or cyborg, many upper-limb prosthesis users feel lucky to be riding the cool wave of advanced technologies. It's a natural trend for a culture that places a high value on selfexpression, triumph over adversity, and the aesthetics of new and emerging technology.

Dodson has observed that the visibility of advanced upper-limb prosthetic systems gives some of his patients a platform for shedding light on what might be thought of as a disability. "I think it can be a very powerful tool if the person wearing it wants it to be," he says. "Angel uses her prosthesis as an opportunity to demystify her situation, to explain that she is not any different than anyone else because of her limb absence."

Wells sees advanced technologies as an important way to increase the acceptance rate of upperlimb prostheses. "As a prosthetist, I'm in this world to help people, and it doesn't help people when they don't wear their prosthesis," he says. "So if looking high-tech or robotic or cyborg leads to greater acceptance of the prosthesis, it probably leads to greater utility, and that is something that I like to see." O&P EDGE

Sherri Edge is a writer and video producer. She has specialized in marketing and communications in the prosthetics industry for more than 20 years, and her work has appeared in numerous prosthetic journals, magazines, and reference books.

