

Patient/Family/Lay Summary: FON Case Review Conference 2022

Coordinated by: Lucile Packard Children's Hospital at Stanford University

Topic: Beyond the Heart: Tackling the Social, Emotional and Educational Challenges of Kids with Fontan Hearts

The Problem

The myriad of physical and neurodevelopmental comorbidities associated with Fontan physiology affect not only physical health but also mental health and school success. Conversely, mental health and school success contributes significantly to physical health (think medical compliance, adherence to healthy behaviors such as exercise and diet, and overall well-being). In caring for Fontan youth, addressing the challenges associated with mental health needs and school struggles can go a long way in improving overall health and well-being. However, medical care teams, families, and patients are often lack awareness, training, tools and resources to address these challenges.

Clinical Course of the Cases Presented

15 yo male with double outlet right ventricle, s/p Y-graft extracardiac Fontan, referred to our Single Ventricle Program at age 11. In the 2 years prior to his SVP visit, he had progressive fatigue and exercise intolerance; he was previously very active, playing soccer and basketball, but now tired after running 2 blocks. He had not been sleeping well, had frequent headaches and was struggling in school, getting mostly Fs in 6th grade. He was subsequently diagnosed with sleep apnea and prescribed oxygen for sleep at night, which significantly improved his daytime energy. He underwent neuropsychological testing and was diagnosed with both attention deficit hyperactivity disorder and major depressive disorder. His primary care physician was able to prescribe medication for ADHD, but he struggled with finding a consistent therapist to treat his depression. He was eventually able to get both 504 and IEP plans in place, and his grades improved in high school. In the intervening 4 years, he was also diagnosed with PLE (with diarrhea, low albumin). He currently struggles with consistently taking prescribed medications. He has started to see a therapist regularly, enjoys hanging out with friends and playing guitar, and is participating in an exercise training program for Fontan youths. *Per mom, "The doctors kept telling me about his heart and getting his heart checked, but really it was his mental health that needed help, and no one was paying attention to that."*

Important Points, Lessons Learned and Potential Solutions

- Regular psychological and developmental screening is needed for all children with CHD
- All members of multidisciplinary teams providing care for single ventricle patients (nurses, social workers, therapists, cardiologists) should receive education and training regarding mental health and developmental assessments

- Identifying and addressing mental health and school concerns can greatly impact physical and medical health
- Cardiology care teams can partner with pediatricians, schools, and community resources on identifying and addressing mental health and school concerns
- Pediatric mental health support continues to be a challenge due to availability of mental health providers; creative solutions (such as including social workers, parent mentors, outsourcing, partnering with school resources) are needed