



GLOBAL

DOWN SYNDROME FOUNDATION®

Science & Society Symposium for Families:
Advocacy, Awareness & Fundraising

***Engaging the Press, Self-Advocates & Celebrities to
Raise Awareness & Funds***

Manuel Velázquez, Vice President, DOWN ESPAÑA
Michelle Sie Whitten, Co-Founder, President & CEO

Saturday, June 8, 2019 • T21RS Biennial Conference, Barcelona

What We Will Cover

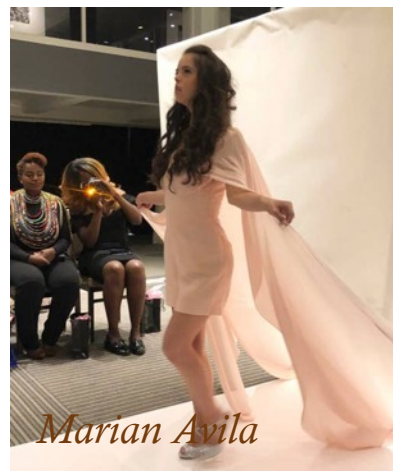
❖ Examples from Spain

- Press, Self-Advocates, Celebrities
- Examples of Success
- Challenges
- What YOU can do

❖ Examples from the US

- Press, Self-Advocates, Celebrities
- Examples of Success
- Challenges
- What YOU can do

❖ Q&A/Thank YOU



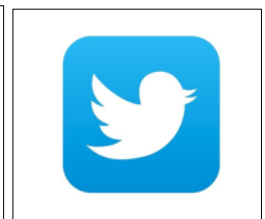
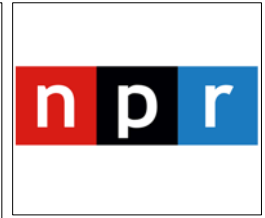
“PRESS” in the U.S.

❖ Public Relations (PR), Marketing, Communications

- Have overlapping meanings and functions
- One can be a subset of the other
- PR can include government affairs

❖ For the purposes of this presentation

- Positive exposure of your organization, work, campaign, and/or constituents
- Traditional media outlets
 - Print, Radio, Television (can include advertising)
- Social Media as of Feb 2019 (MAUs)
 - Facebook - 2.23B; YouTube - 1.9B
 - WhatsApp - 1.5B; Messenger - 1.3B, WeChat - 1.06B
 - Instagram - 1B
 - QQ, Tumblr, Qzone, Tik Tok, Sina Weibo
 - Twitter - 335M MAUs, (only 280 characters, 140 for NE Asian); 1-800 equivalent for customer service



The Importance of Press for Nonprofits

❖ Nonprofits, Not-for-profits, Non-governmental organizations (NGOs)

- 1.6M in the US, tax exempt according to the IRS
- Over 1M of nonprofits in the US are 501(c)3 organizations including religious, educational, charitable, scientific and literary organizations
- 501(h) election for a 501(c)3 for lobbying

❖ Importance of Press for Nonprofits

- FUNDRAISING - Major gifts tied to work results; Events tied to work results; Programs & Services; Acquisition of constituents including membership
- LEGISLATION - Petitions, Hearings, Briefings, Actual legislation (usually implies funding)
- AWARENESS & EDUCATION (has to be funded)
 - Facts, New Facts (Access, Care, Education, etc)
 - Societal perception changes; Logistical/Direct changes to implementation

❖ Global is a 501(c)3 with a 501(h) designation



How to Get Press

❖ Create or grow your press pipeline - Local and/or National

- **Do your homework!**
- Who covers what areas of interest - Human Interest, Health, Education
- Who has covered Down syndrome, disability, or niche groups well
- When is it timely to get coverage (e.g. World Down Syndrome Day, anniversary of a disability legislation)
- Prepare written materials - press releases, media alerts, suggested Q&A/fact sheets, and/or pitches
- Be in touch with your press representatives and media outlets year round and not just when you want coverage

❖ Focus on the people you serve - People with Down syndrome (self-advocates)

❖ Recruit Celebrity when possible

Global Press Clippings



2018 Press Clippings

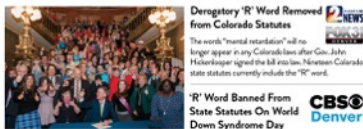


2017 PRESS CLIPPINGS



Global Press Clippings

GLOBAL'S EVENTS & PROGRAMS WORLD DOWN SYNDROME DAY



Derogatory 'R' Word Removed from Colorado Statutes
The word "mental retardation" will no longer appear in any Colorado law after Gov. John Hickenlooper signed the bill into law. New Mexico state statutes currently include the "R" word.



'R' Word Banned From World Down Syndrome Day
Gov. John Hickenlooper signed an act that will strip the word demeaning people with Down syndrome and other mental disabilities and conditions, removing its appearance in hundreds of statutes. Hundreds attended Wednesday's signing ceremony, organized by the Global Down Syndrome Foundation.



Celebrating World Down Syndrome Day
Global Down Syndrome Foundation President & CEO Michelle Sue Whitman and Ambassador Dr. Ondra Duncan discuss World Down Syndrome Day.



Why the Capitol Will Be Lit in Blue and Yellow
Governors and First Spouses around the country will participate in the "Light the Way Campaign" celebrating the empowerment of people with Down syndrome. The Global Down Syndrome Foundation encourages editors to leave them with #GlobalLightTheWay.

coloradopolitics, DAILY WIRE, TELEUNDO DENVER, StarTribune, THE JOURNAL, DILLINGER

GLOBAL'S EVENTS & PROGRAMS



Jimmy Connors Hits the Court for Global Down Syndrome Foundation
The community came out in full force, including tennis legend Jimmy Connors, to support athletes at the Global Down Syndrome Foundation's Dare to Play Tennis Camp.



Tennis Icon Jimmy Connors Supports Global Down Syndrome Foundation
Jimmy Connors was among the tennis players at the Dare to Play Tennis Camp at the Global Down Syndrome Foundation's annual Dare to Play Tennis Camp in Denver.



Tennis Legend Jimmy Connors Visits Colorado
One of the greatest players in tennis history was in Denver Friday, sharing his knowledge with every special group of youngsters over at the Gates Tennis Center.



Why is Ed McCaffrey Coaching High School Football?
McCaffrey founded SportsEdify, which organizes sports camps for kids, and Dare to Play Football Camp. Ed McCaffrey & Luke Stahmer discuss Global's Dare to Play Football Camp.

3-time Super Bowl champ, Broncos All-Star, and Volar Head Coach Ed McCaffrey & Luke Stahmer discuss the Global Down Syndrome Foundation's Dare to Play and Dare to Cheer camps.

2018 Press Clippings

GLOBAL'S EXPANDING REACH



'My Son Has Down Syndrome' and He is My Greatest Teacher
Amanda Bush had been a mother for four months when she and her husband Mike discovered that their newborn son, Michael, had Down syndrome. A model and actress who's worked everywhere from Paris and Seoul to Milan and Sydney, for clients like Target, JC Penney, cult denim label True Religion and Lancôme - Amanda is now also an advocate for Down Syndrome research, working closely with the Global Down Syndrome Foundation to raise funds and awareness.



Paddling for gold: The Seattle Times
Adelman goes from White House to Special Olympics Ambassador
From speaking at the United Nations and visiting the White House as an advocate for the Global Down Syndrome Foundation, to playing sports like cheerleading and soccer, Down Adelman has always been in the occasion. Her next big goal: A stand-up paddle board gold medal at the Special Olympics USA Games in Seattle.



Beaver Dam Nongenarian Becomes Children's Author
Beverly Berling Davidson is a newly published author at the age of 91. Her children's book, "BOWIE" was recently released by Archway Publishing. Davidson not only wrote the story, but painted the illustrations as well.



The royalties from "BOWIE" will be donated to Shriners Hospitals for Children, Global Down Syndrome Foundation, S-waves and Exotic Cry.

Global Down Syndrome Foundation

GLOBAL'S EXPANDING REACH INTERNATIONAL



Uganda celebrates World Down Syndrome Day 2018!
Global Down Syndrome Foundation joined forces with the Global Livingstone Institute to bring local organizations and families with Down syndrome together in Uganda's capital city of Kampala to celebrate World Down Syndrome Day. The theme of the event was social inclusion, and over 300 people came out to celebrate and create awareness about Down syndrome.



I Know Kati Concert Series in Uganda
Global Livingstone Institute hosted their Kikwaka Concert Series featuring performances of thousands of people to dispel common myths about Down syndrome & share accurate information. Embuka Kati is a training local stage medical teams across Uganda how to identify, connect, & support families who have a child with Down syndrome. Global Down Syndrome Foundation organizes and collaborates on their important international work.



Amanda at @Glowethnicall
After sharing that their son had been diagnosed with Down syndrome, the new normal for Amanda and her husband, Mike, became about spreading awareness and acceptance of the condition.



Taniqua Chan a worda scogi modelo international 2018
Pa representante Amada na Denver Colorado den a show di "Be beautiful be yourself" ORANJESTAD (ARUBA) "Global Down Syndrome Foundation" organization na Merica ta unie publico sin fin di fuentu outa dedica su mes pa significativamente mehorando bida di hende cu Down Syndrome, pa medio di ligamentu investigacion den tanto cu medio educacion y sintonia.

2018 Press Clippings

GLOBAL'S EVENTS & PROGRAMS



Be Beautiful Be Yourself Dance Winter Performance
The Global Down Syndrome Foundation's Be Beautiful Be Yourself Dance program is comprised of three sessions of classes serving individuals with Down syndrome ages 5-15. The ballet program is a collaboration between Global, the Star Center for the Performing Arts and the Colorado Ballet.



Global Down Syndrome Foundation Awards Over \$550K in Educational Grants
This year, the Global Down Syndrome Foundation (Global) awarded \$75,000 to nine of its member organizations, bringing the total given through its Educational Grants program to over \$550K. Since 2012, Global has awarded grants to 60 innovative educational programs developed by local, national and international Down syndrome organizations.



Isaac Slade Private Concert Hosted by the Global Down Syndrome Foundation
The Down Syndrome Affiliates in Action Conference is focused on improving the way Down syndrome organizations deliver programs/services and operate as a nonprofit. As part of this event the Global Down Syndrome Foundation is hosting an Isaac Slade private concert at the Gothic Theatre.

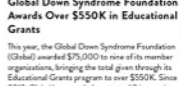


Global Down Syndrome Foundation

GLOBAL'S EVENTS & PROGRAMS



The Daniels Fund Gives \$100K For Global Programs
Global's Health and Wellness Programs hit the ground running in 2018, with a game-changing grant from the Daniels Fund for the third year. The grant helps Global improve and grow its seven life-skills programs. Global is using this generous award to implement additional formal instruction and P.E. training and safety seminars and reach even more new individuals with Down syndrome.



Global's Employment Grants Employ 48 Individuals with Down Syndrome
The Global Down Syndrome Foundation awarded \$16,900 to 9 organizations through their Self-Advocate Employment Initiative Grants. The Grants, a benefit of Global membership, empower local Down syndrome organizations to hire individuals with Down syndrome. The grants continue to expand their reach in 2018, employing 16 self-advocates, for a total of 48 individuals hired since the grant initiative inception in 2016.



HAWAII NEWS NOW



MARKETS INSIDER

2018 Press Clippings

GLOBAL'S RESEARCH & MEDICAL CARE SIE CENTER FOR DOWN SYNDROME PUBLICATIONS



Differentiating Behavioral Characteristics of Individuals with Down Syndrome
Children and young adults with Down syndrome can demonstrate increased behavior problems compared to their typically developing peers through childhood and adolescence. Results from this study indicate that a measure to more effectively capture and differentiate problem behaviors in children and adolescents with Down syndrome is greatly needed.



Clinical Characteristics & Risk Factors for Developing Pulmonary Hypertension in Children with Down Syndrome
Pulmonary hypertension is common in children with Down syndrome, is typically transient, and related to CHD or PPHN but can occur in the setting of respiratory disease such as obstructive sleep apnea, intermittent hypoxia, and recurrent pneumonia. People with Down syndrome have a shorter life expectancy, in part because of the high incidence of cardiopulmonary comorbidities.



Understanding Hearing and Hearing Loss in Children with Down Syndrome
The prevalence of hearing loss and abnormal middle ear status is high in the pediatric population with Down syndrome (DS). This study evaluated the prevalence of permanent and transient hearing loss, the use of hearing aids as a recommendation, and middle ear dysfunction in children with DS.

Authors: Emily Nightingale, Patricia Voss, Kristy Walther-Morse, Dan Dawkins, and Francis Hickey.

Global Down Syndrome Foundation

GLOBAL'S RESEARCH & MEDICAL CARE EXPERT COVERAGE IN EVERYDAY HEALTH SERIES



Raising a Child With Down Syndrome: What to Expect
Wondering how growing up will be different for your child with Down syndrome? Here's an overview of how your child will develop physically, cognitively, and socially. Michelle Sue Whitman talks with Everyday Health about what parents should expect.



Complications and Other Health Problems Linked to Down Syndrome
People with Down syndrome are at an increased risk of developing a host of health conditions (including Alzheimer's disease, obesity, and heart disease) that are important for people with Down syndrome (and for those caring for them) to know what they're predisposed to," says Michelle Sue Whitman. With close monitoring, some complications may never become an issue.



Treatments, Therapies, and Special Services Can Help People With Down Syndrome Manage Their Disabilities
Services to help people with Down syndrome have changed dramatically in the past half century. In the 1960s, when a baby was born with Down syndrome, the parents were offered the option to institutionalize the child. Now, organizations like the Global Down Syndrome Foundation want to educate families.

How Having Down Syndrome Affects Everyday Living in Adulthood
The outlook for adults with Down syndrome has changed drastically over the past few decades. In the early 1900s, a person with Down syndrome was expected to live less than 10 years. Today, many people with the genetic disorder live into their sixties.

2018 Press Clippings

Focus on the People You Serve

❖ People with Down Syndrome and their Families

- Human Interest Stories are the MOST POWERFUL
- The stories can crosscut issues of health, research, education, independent living, marriage, employment AND can be tied to an issue, event, legislation, etc
- FYI - WITHIN the Down syndrome community in the US we may call those with the condition Self-advocates

❖ Global's Philosophy

- “AND” not “OR”
 - Stories can be about a person with Down syndrome AND an important campaign
 - Events can be about Awareness AND Fundraising
 - Programs can be free to participants AND be revenue generating
 - Legislation can benefit Global AND the entire Down syndrome research field
 - Press is an important means to and end solidifying existing supporters and attracting new ones
- PREPARE YOUR SELF-ADVOCATES AND PRACTICE!

❖ Global's Major Successes

- Advocating in Washington DC and moving a 20 year trend of \$14M to \$22M in Down syndrome research funding at the National Institutes of Health to \$98M in 2020 - KEY TO SUCCESS? Frank Stephens 5 min testimony to Congress that went viral
- Advocating at the Colorado Capital for local legislation on World Down Syndrome Day - KEY TO SUCCESS? Ari, a little boy with DS wearing “I love homies with extra chromies” who went viral on social media with over 1M views on Global's Facebook

Global Down Syndrome Foundation Ambassadors



CC Mullen
2019



Sam Levin
2018



Marcus Sikora
2017



Louis Rotella
2016



Clarissa Capuano
2015



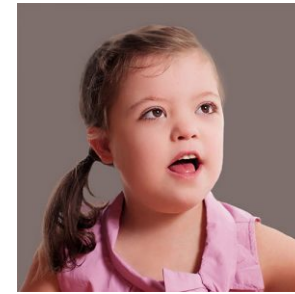
Steven Dulcie
2014



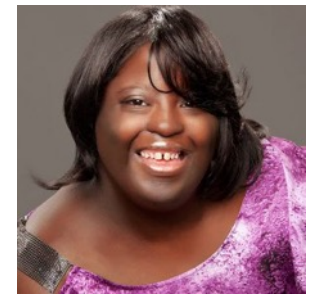
Katherine Norton
2014



Cole Rodgers
2013



Samantha Stevens
2013



DeOndra Dixon
2011



Alexander Sessions
2011



Katherine Winfield
2010



Chase Perry
2009



Sophia Whitten
2008

Recruit Celebrities When Possible

❖ Celebrities DO attract people to your cause

- “AND” not “OR” = Global Events aim to have Celebrities AND Self-Advocates AND Government Officials AND important philanthropists AND corporate donors...

❖ Find Celebrities who are connected

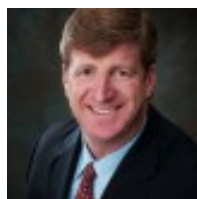
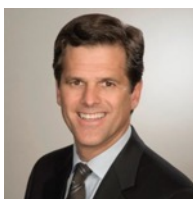
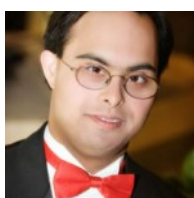
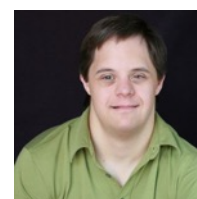
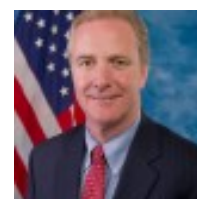
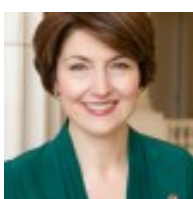
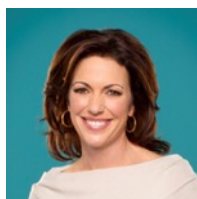
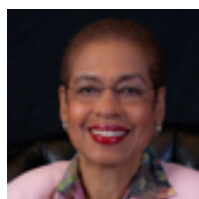
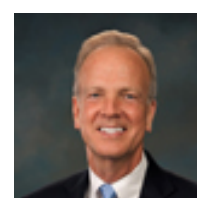
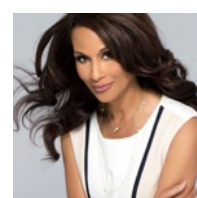
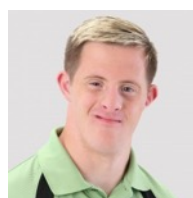
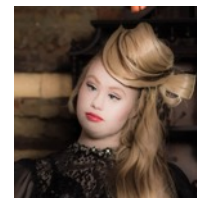
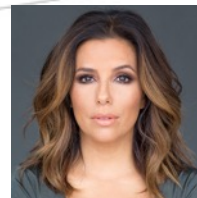
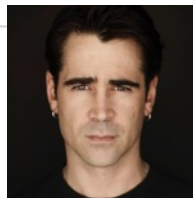
- To Down syndrome, to Intellectual and developmental disabilities, to disabilities, to social justice, to human and civil rights
- PREPARE YOUR CELEBRITIES AND THEIR HANDLERS!

❖ IF the economic model makes sense do not be afraid to pay for a Celebrity

- The Be Beautiful Be Yourself Fashion Show is the largest fundraiser for Down syndrome in the world selling out each year at 1,400 participants and grossing over \$2M (in the US we aim to keep costs at 30% of total maximum)



Quincy Jones Exceptional Advocacy Award Recipients



Roy Blunt, 2019
 Cheri Bustos, 2019
 Zack Gottsagen, 2018
 Colin Farrell, 2018
 Eva Longoria, 2017
 Madeline Stuart, 2017
 Frank Stephens, 2016
 Jamie Brewer, 2015
 Anna and John J. Sie, 2015
 Brad Hennefer, 2014
 Beverly Johnson, 2014
 Jerry Moran, 2014
 Eleanor Holmes Norton, 2014
 Tim Harris, 2013
 Kyra Phillips, 2013
 Cathy McMorris Rodgers, 2013
 Chris Van Hollen, 2013
 Luke Zimmerman, 2012
 Jamie Foxx, 2012
 Sujeet Desai, 2011
 John C. McGinley, 2011
 Pete Sessions, 2011
 Tom Harkin, 2011
 Karen Gaffney, 2010
 Patrick J. Kennedy, 2010
 Timothy P. Shriver, 2010
 DeOndra Dixon, 2009
 Quincy Jones, 2009

Challenges

- ❖ TIME! This is our biggest challenge. A lot of press acquisition is free from cost...
- ❖ COST! Many organizations are ready to go to the next level with press but are prevented by costs
 - Cost of headcount to do more in-depth work
 - Cost of software that allows press monitoring



❖ POTENTIAL FIXES

- Find a day to focus on planning and strategizing
- Part-time Public Relations person
- Focus on press for a finite campaign or event and grow your press from there
- Find a donor who is willing to underwrite celebrity

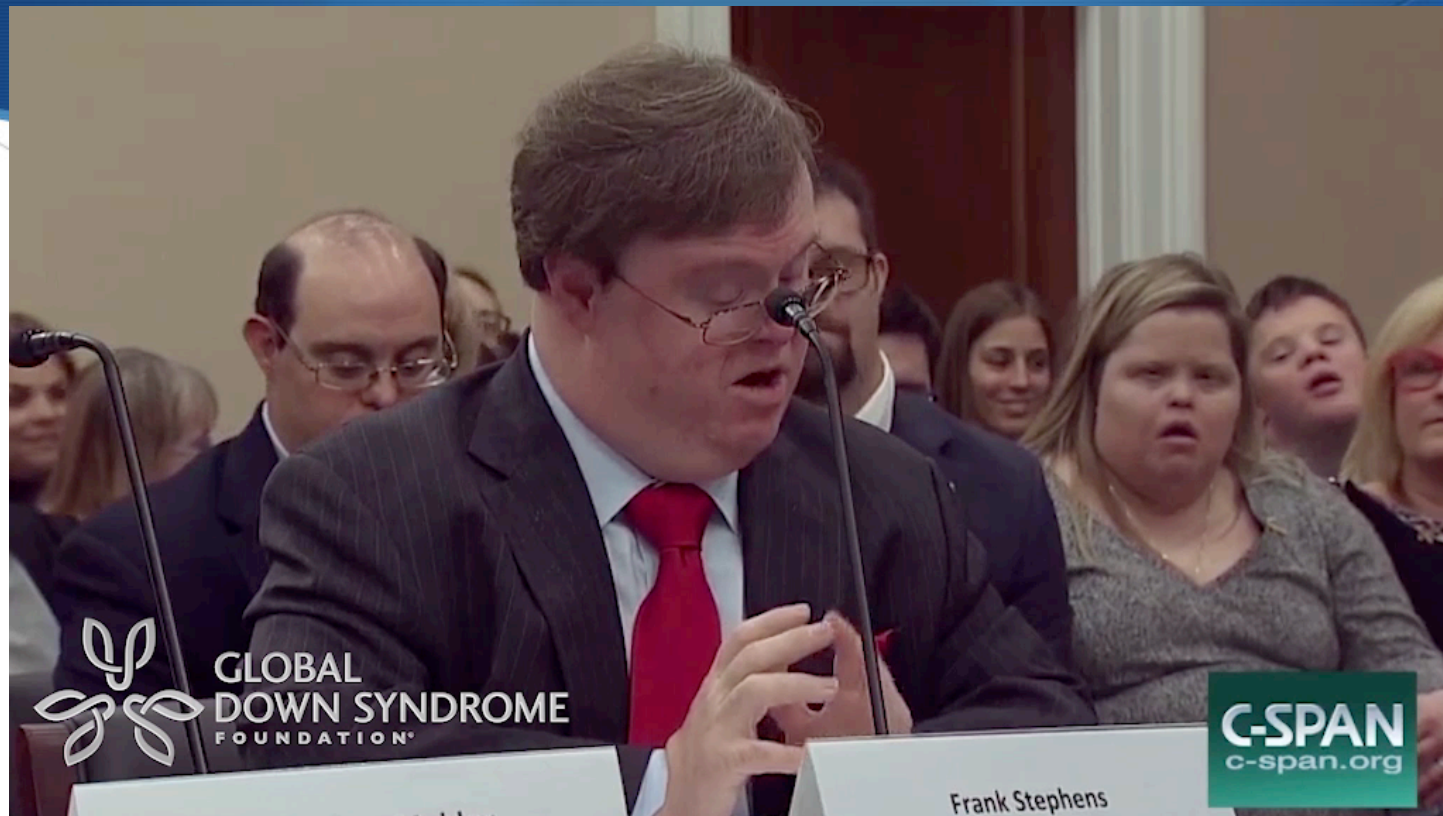
What You Can Do!

- ❖ Create a simple press plan for your organization or for yourself/a Self-advocate!
- ❖ Help expand press with the creation of more pitches and stories and cultivation of more reporters and media outlets
- ❖ Communicate press success through social media, your website and email blasts
- ❖ If you have the budget, track your press reach
- ❖ Always follow-up and thank press people, Self-advocates who are featured, celebrities, and anyone else who made it happen



THANK YOU from our GLOBAL TEAM!

Frank Stephens testifies Before Congress = 100M+ views resulting in a historic **71%** increase of NIH's Down syndrome research budget from \$35mil in FY2017 • to \$60 mil in FY2018 • to \$77mil in FY2019



“I am a man with Down syndrome and my life is worth living!”
~ Frank Stephens