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

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

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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
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
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
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
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