

# My 21000

A DAY IN THE LIFE WITH CYSTIC FIBROSIS

August 27, 2014



# My21000 Goals & Objectives

To create connections between adults living with cystic fibrosis (CF) and new audiences while broadening awareness around the challenges of living with CF and promoting the overall mission of curing the disease.

Increasing awareness of CF and growing engagement beyond the “inner circle” is challenging and will require innovative thinking, particularly to reach the Millennial generation—young adults between the ages of 18 and 34 years old.

Capturing the attention of Millennials is especially difficult, as they tend to be more socially and digitally connected than other demographics. They receive numerous new messages across multiple platforms every minute, which makes breaking through all of that online clutter challenging...but not impossible. By providing a robust digital platform that enables people living with CF to create authentic, rich, and immersive storyscapes, the My21000 initiative can bring their compelling stories of inspiration, grace, humor, courage and compassion to the rest of the world and generate new conversations, connections, friends, and engagement.

While Millennials are not the only audience, they are the primary targets for this initiative. Working closely with the Cystic Fibrosis Foundation’s (CFF) cadre of CF adults who are willing to share their stories and dialogue with new audiences, we believe these Millennials are positioned to become powerful ambassadors for the cause of curing CF and “adding tomorrows” through stories that celebrate the shared human experience of 21,000 breaths every day.

## MILLENNIAL FACTS

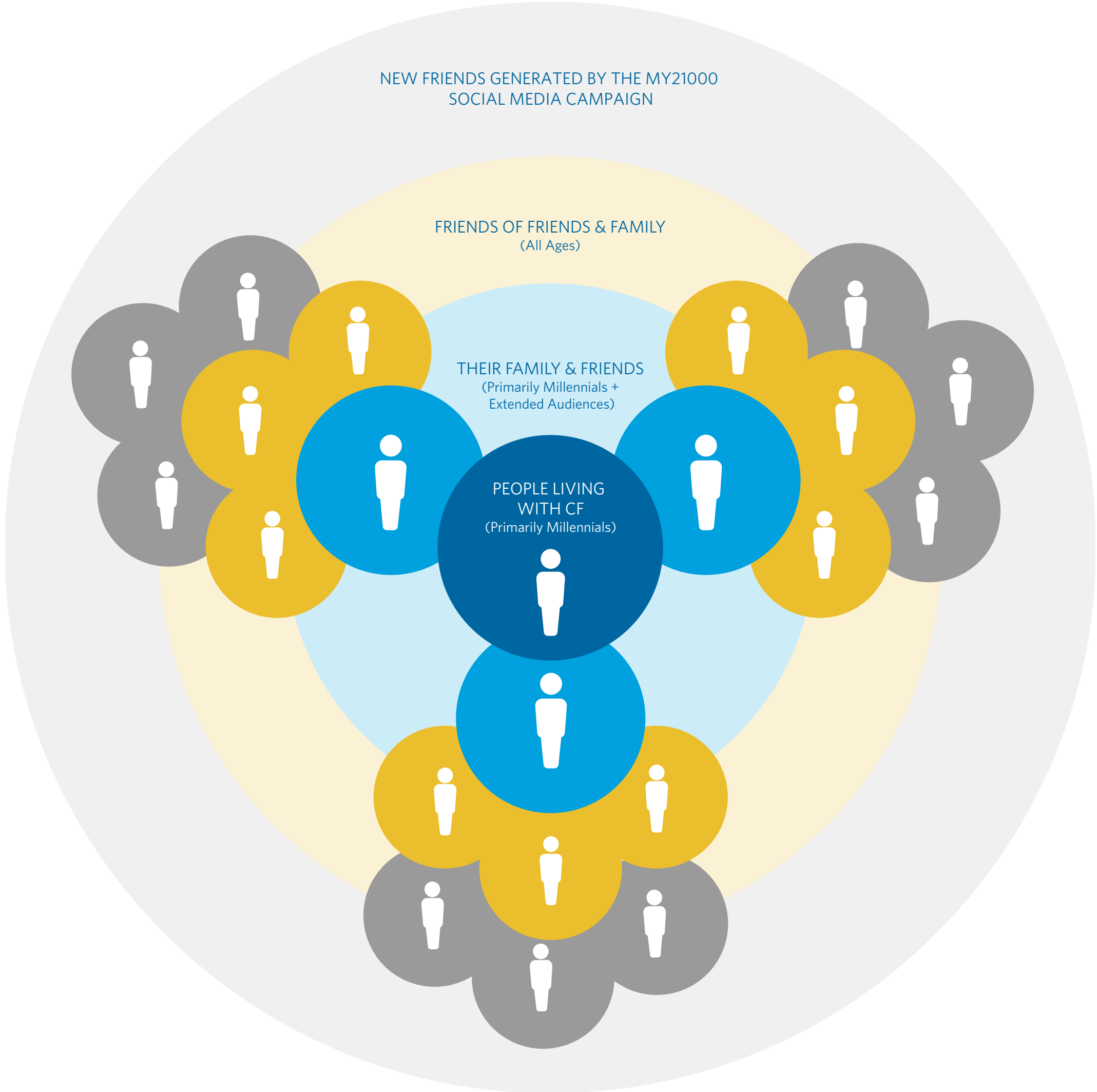
- Millennials are more health-conscious than older generations
- 81% have donated money, goods or services
- Millennials are more tech-savvy than older generations
- Millennials love social media
- 61% of Millennials are worried about the state of the world and feel personally responsible for making a difference
- Millennials are the children of the Baby Boomers, and there are about 95 million of them, comprising 30% of the population
- Millennials are better educated than prior generations

# My21000 Goals & Objectives

While it matters how difficult those 21,000 breaths might be, it's much more important to know what each of us is doing with them. The My21000 campaign will generate new friends through the natural expansion of social media. These friends will care about CF because it affects someone they now know. They will no longer take each day of 21,000 breaths for granted and they will be excited to share this experience with other friends, communities, and networks.

In the pages that follow we have outlined our preliminary thinking and proposed approach to this incredibly important and exciting initiative.

# Going Beyond the Inner Circle



IT'S NOT A BAD IDEA TO OCCASIONALLY  
SPEND A LITTLE TIME THINKING ABOUT  
THINGS YOU TAKE FOR GRANTED. PLAIN  
EVERYDAY THINGS...LIKE BREATHING.

# Executive Summary

## Fostering a Community & Building Awareness

Most people not closely connected with someone living with CF are unfamiliar with the daily challenges of living with CF. They likely don't have an appreciation for the obstacles that have to be overcome in order to participate in society.

CFF has developed the My21000 concept to serve as the organizing idea behind a groundbreaking initiative to connect adults living with CF with others, broaden the public's awareness of what it means to live with CF and give them a personal reason to care. In order to bring the My21000 concept to life, CFF will create a robust social media platform where people living with CF can share their stories, create meaningful connections with new friends, and in the process build greater awareness of what it really means to live with CF every day. It's about real people, with real stories, who really want to share their experiences with the world, to become friends with people who care about their experiences, to become ambassadors for their common cause, and to define how they use their 21,000 breaths every day.

The intention of the My21000 campaign is to create an immersive experience, a "world" that invites CF adults and other people ("outer circle") to "jump in" and become part of the narrative. The concept of "storyscape" is to build a platform across all social media platforms that enables participants to become evangelists by telling their own stories, sharing stories of others that touch them within their own social media and other networks, and extending the impact of this valued—and valuable—conversation far beyond what expensive brand advertising could accomplish.



### ORGANIZING IDEA

#### My21000

Each person takes 15 breaths per minute, or 21,000 breaths per day, without thinking about it.

Someone with CF works very hard every day for those 21,000 breaths...what have you done with your 21,000 breaths today?

# Executive Summary (continued)

People don't just want to be told a story; they want to be part of a story. There is more power in starting our story from an "organizing idea"—an active expression meant to inspire experiences. The My21000 concept can drive participation because it connects with people who don't have or even know about CF, yet these people can become part of the story or contribute to it based on their own 21,000 breaths. And once they are part of the story, it becomes an important personal experience, one that could compel sharing with others.

Enabled by advancements in technology, this natural storytelling dynamic can reach many more people, so affinity and community can be established more easily and faster than ever before.

TO YOU THIS  
IS 35 STAIRS...

for me this is Mount Everest.

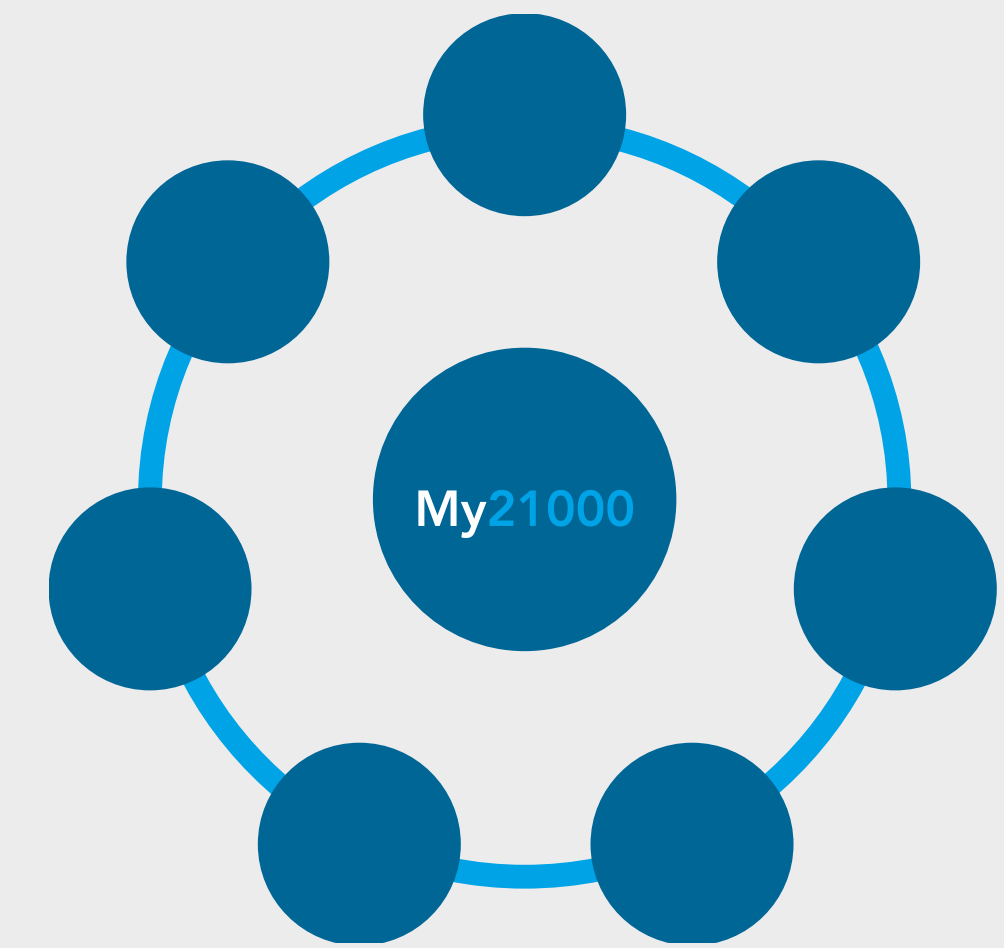


## My21000 & Social Media

Creating a website alone simply would not accomplish the goals or objectives established by CFF for the My21000 initiative; it will require a much more robust approach. After having thoroughly considered CFF's goals and objectives, we recommend creating a dynamic, immersive, socially connected community platform where adults living with CF can create personal profiles, share their My21000 stories through a variety of mechanisms, and connect their favorite social media networks to the community thus sharing their stories with the larger world as ambassadors for the CF community to the “outer circle.”

Those who elect to share their experiences can have their stories published on branded “My21000” social media networks including Facebook, Twitter, Pinterest, YouTube, and other (TBD) channels, in addition to their own social media networks. By creating a socially connected community platform, CFF can empower adults living with CF to broaden awareness for their cause in a way that was never before possible.

To be effective in the social media environment, we must understand that consumers are in control of what they pay attention to—and what they ignore. We hone in on only the information we care about. The challenge is not so much about getting your message to an audience, as it is about getting consumers to let you in and getting them to care. Social media consumers filter messages by asking themselves, “Why should I let you be part of my world?” Rather than pushing ads at consumers, social media works because people are compelled to send impactful content to their friends with, “Did you see this?”



### EXPERIENCE SCAPES

#### My21000 & Social Media

My21000 will take a hub and spoke approach to broadening the conversation around what it means to live with CF. As a stand-alone website My21000 will be at the hub and users will define their spokes, that being their preferred social media networks. When users connect their social media networks to My21000 they are able to share their stories across a variety of networks.

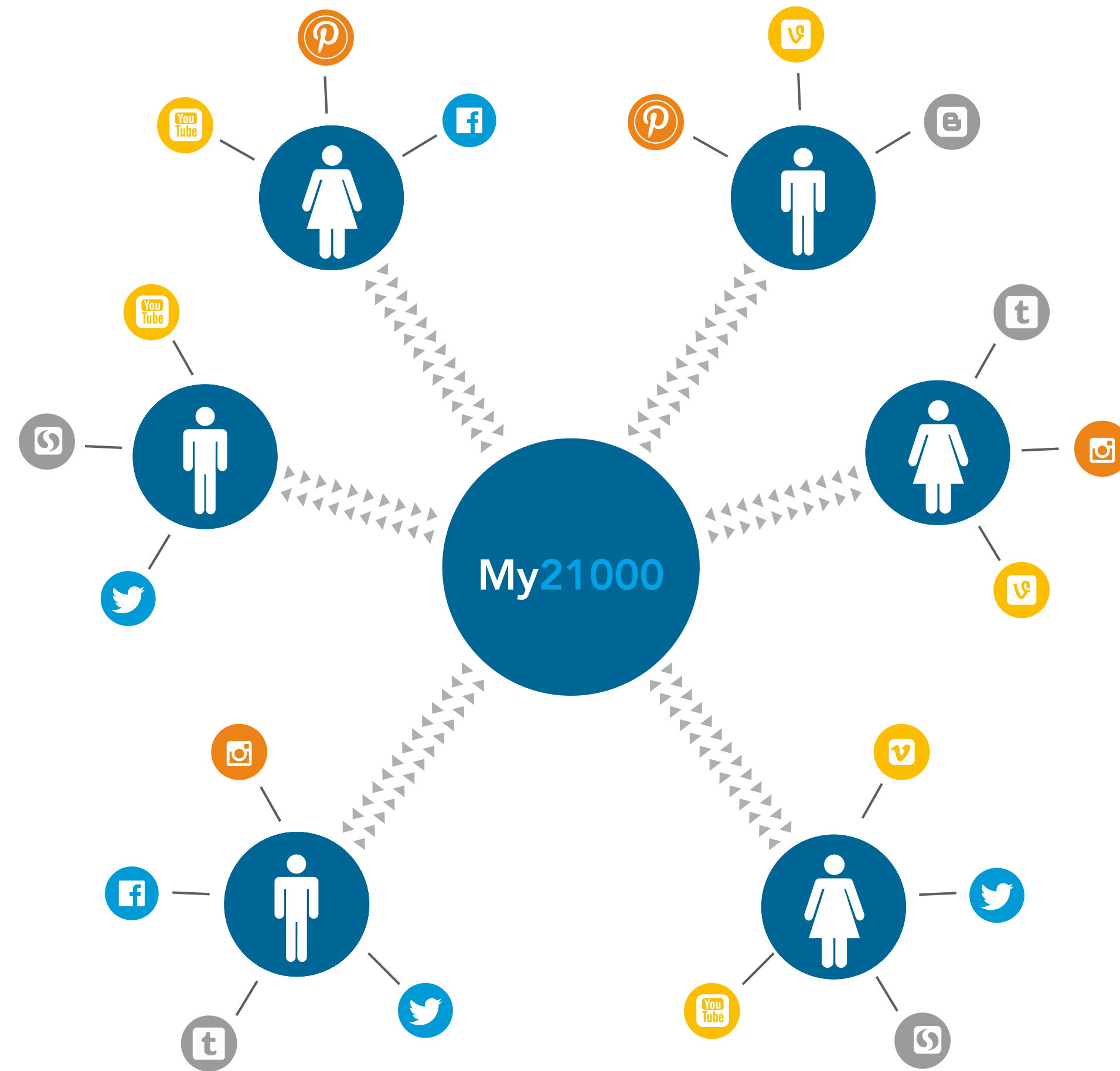
## My21000 & Social Media (continued)

One of the most important resources of CFF is the power of the personal stories of people with CF and their families. A personal relationship with someone with CF has been the most powerful driver of the incredible financial support raised to fight CF.

A CF adult story is a story that “matters”—it is authentic, personal, meaningful and human. It is the story of someone who has faced long odds, dealt with important issues of survival, learned to accept support graciously, and faces the future with courage. But a CF adult story is also the story of each of us, except that this person lives with CF. They have the same values and human aspirations as others, but to someone who has outlived their life expectancy, life seems a bit more precious. The intended audience of the My21000 campaign consists of those people who want to hear this story and make it part of theirs.

## Sharing their Stories with the World

Every user will have the chance to create their own storyscape around how they use their 21,000 breaths every day...to share their stories, daily challenges, dreams and aspirations with the world through a robust, socially connected community platform.



### MY2100

#### It's All About Personal Stories

Each person takes 15 breaths per minute, or 21,000 breaths per day, without thinking about it.

Someone with CF works very hard every day for those 21,000 breaths...what have you done with your 21,000 breaths today?

Share your story.

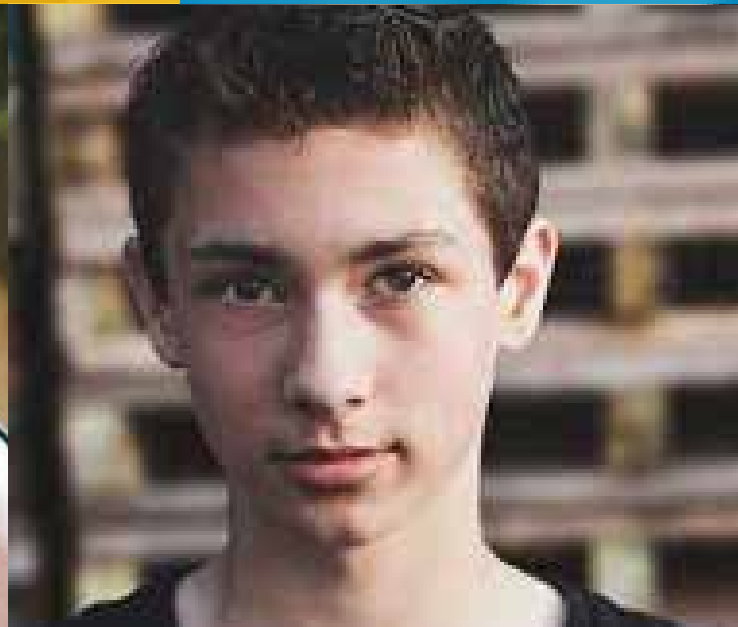
# FEELING ISOLATED IS MY REALITY.

I can't share space with people  
like me...and it hurts.





# CREATING My21000



# Creating My21000

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## 1. VISION & STRATEGY

AUGUST 18, 2014

- Establish strategic goals and objectives
- Define key performance indicators (KPIs)
- Hold half-day workshop focused on information architecture, user experience, design/creative, and platform functional requirements
- Develop brand strategy for My21000
- Develop project plan
- Select Open Source social media software platform

## 2. DESIGN

- Develop information architecture/ sitemap
- Develop wireframes
- Develop brand/visual identity for My21000
- Develop design concepts
- Revise selected design concept
- Finalize design templates
- Develop visual design assets for site

## 3. DEVELOPMENT

- Develop HTML, CSS, and jQuery/JavaScript for site
- Develop technical specification for platform based on the selected Open Source social media software platform
- Create theme for Open Source social media software platform
- Develop any required software functionality/integrations based on functional requirements document
- Integrate and configure any required third-party software modules
- Conduct user acceptance testing and provide super user/admin training

## 4. MARKETING

DECEMBER 15, 2014

- Develop digital marketing strategy and playbook
- Develop branded assets for social media platforms
- Develop campaign assets

# Vision & Strategy

The goal for the vision and strategy phase is to develop a comprehensive strategic plan for My21000 including brand and platform, and to ensure that all key stakeholders have a shared vision of what will be designed, developed, and launched.

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## Activities:

- Project kickoff meeting to establish strategic goals and objectives for My21000 and define key performance indicators (KPIs)
- Hold half-day workshop for brand strategy
- Hold half-day workshop focused on information architecture, user experience, design/creative, and platform functional requirements
- Develop brand strategy for My21000
- Develop project plan
- Select Open Source social media software platform

## Deliverables:

- UX storyboard
  - Functional requirements document
  - Creative brief
  - Project brief
  - Brand strategy deck for My21000
  - Project plan and timeline
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# Design

During the design phase the user experience for My21000 will come to life. The activities in this phase are focused around information architecture, user experience design, and brand identity development.

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## Activities:

- Develop information architecture/sitemap
- Develop wireframes
- Develop brand/visual identity for My21000
- Develop design concepts
- Revise selected design concept
- Finalize design templates
- Develop visual design assets for site

## Deliverables:

- Information architecture/sitemap
- Wireframes
- Final site designs
- Brand identity/visual identity for My21000

# Development

As the user experience has yet to be fleshed out along with the functional requirements for My21000, it is impossible at this juncture to provide detailed and/or fixed pricing. With that said, based on past experience it is more than feasible to estimate low-end and upper-end range for this development initiative.

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## **Activities:**

- Develop HTML, CSS, and jQuery/JavaScript for site
- Develop technical specification for platform based on the selected Open Source social media software platform
- Create theme for Open Source social media software platform
- Develop any required software functionality/integrations based on functional requirements document
- Integrate and configure any required third-party software modules
- Conduct user acceptance testing
- Provide super user/admin training
- Ready and release platform

## **Deliverables:**

- Final HTML/CSS package
- Theme package for Open Source social media platform
- Custom code for functionality (package)
- Any third-party software modules/plugins
- Final package with all assets

# Marketing

The team will develop a marketing strategy and playbook for CFF to use in order to promote My21000, and achieve the goals and objectives outlined in the vision and strategy phase of the engagement. We will also deliver the assets necessary to implement the launch campaign for My21000.

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## Activities:

- Develop digital marketing strategy and playbook
- Develop branded assets for social media platforms
- Develop campaign assets

## Deliverables:

- Digital marketing strategy and playbook
  - Assets for branded social media channels
  - Marketing campaign assets (final TBD)
-



# ENABLING Technologies



# 15 BREATHS EVERY 60 SECONDS...

Each one is a little victory for me.



# Enabling Technologies

## Open Source Simplicity

There are a number of existing Open Source software platforms that can be leveraged to create My21000 including JomSocial, BuddyPress, Dolphin, Elgg, Anahita, and PHPfox, just to name a few. All of these Open Source social media platforms offer all of the requisite functionality to enable and create a robust and engaging experience for My21000. Each platform offers deep integration with a wide variety of social media networks including Facebook, Twitter, Instagram, YouTube, and others. Most of these platforms offer a powerful application program interface that can be leveraged to write additional integrations if needed.

## OPEN SOURCE SM PLATFORMS





# SITE Samples



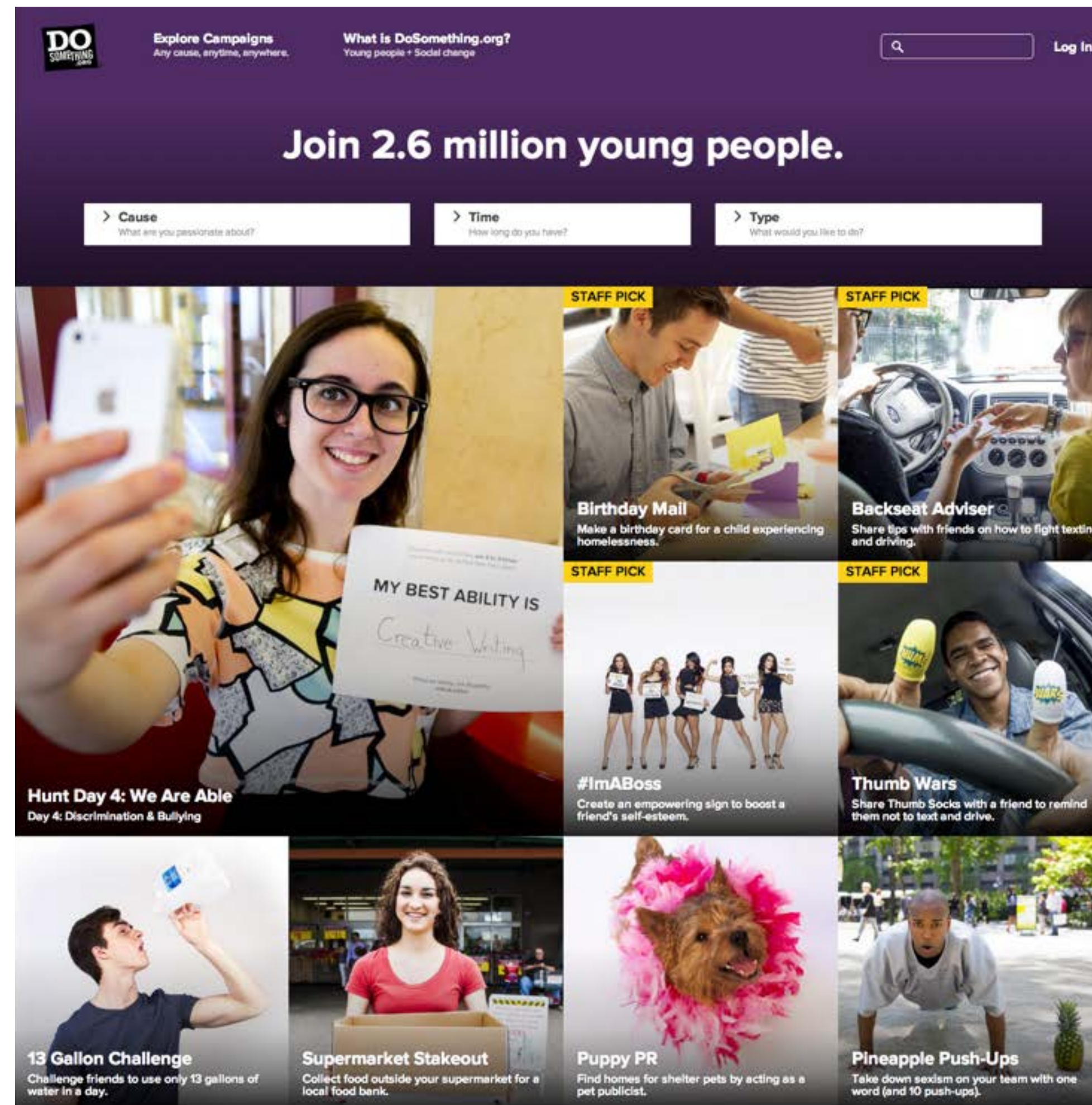
# Site Samples

We searched and searched for a one-to-one example of the type of website envisioned for the My21000 initiative, but unfortunately none exist. With that said, we were able to identify a handful of websites that contain elements of what is imagined for the My21000 initiative. In the pages that follow you will find examples of some of the more robust, innovative online communities launched in recent years.

While these examples are some of the more progressive, community-oriented websites online today they (some of which are cause-oriented) lack the dynamic, rich, immersive, and visually compelling user experience that is visualized for the My21000 initiative.

We feel that the My21000 initiative not only has the ability to help adults living with CF create meaningful connections, share their stories, and in the process broaden understanding of what it means to live with CF, we believe it is an opportunity for CFF to set the benchmark when it comes to creating a cause-based community.

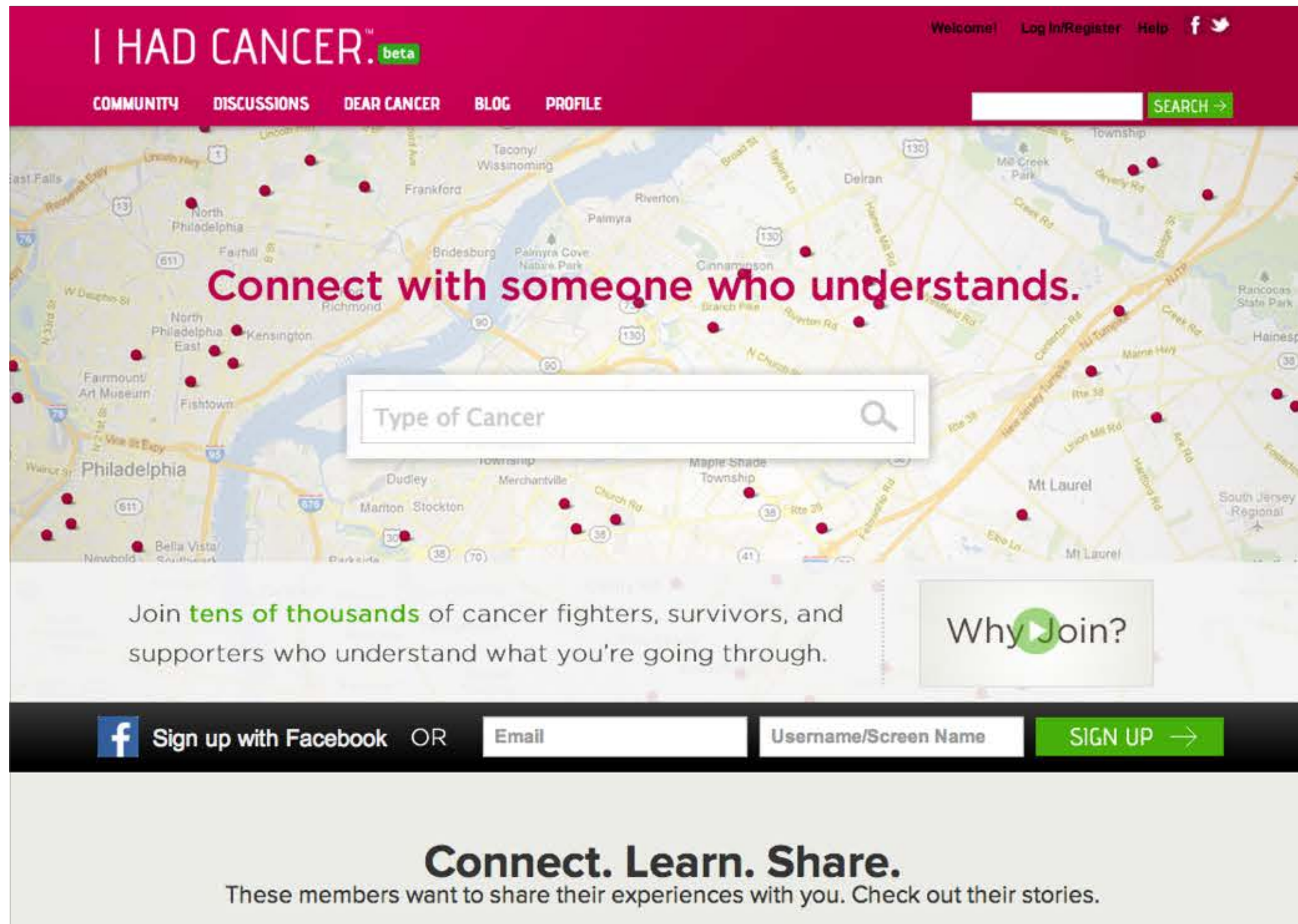
# dosomething.org



## ASPECTS WE LIKE

- The visual representation of content through visual tiles is visual engaging and will appeal to the millennial demographic
- The navigation is simple and easy to use

# ihadcancer.com



I HAD CANCER.™ beta

Welcome! Log In/Register Help f t

COMMUNITY DISCUSSIONS DEAR CANCER BLOG PROFILE

SEARCH →

Connect with someone who understands.

Type of Cancer

Join **tens of thousands** of cancer fighters, survivors, and supporters who understand what you're going through.

Why Join?

Sign up with Facebook OR Email Username/Screen Name SIGN UP →

**Connect. Learn. Share.**  
These members want to share their experiences with you. Check out their stories.

## ASPECTS WE LIKE

- Has the ability to register with a platform (Facebook) you are already active with or create a unique username/password
- Clear call to action
- Has the ability to directly connect with individuals from the group
- Has the ability to search profiles of the community (including by location)
- Has a general discussion board where individuals can ask questions and offer support and advice

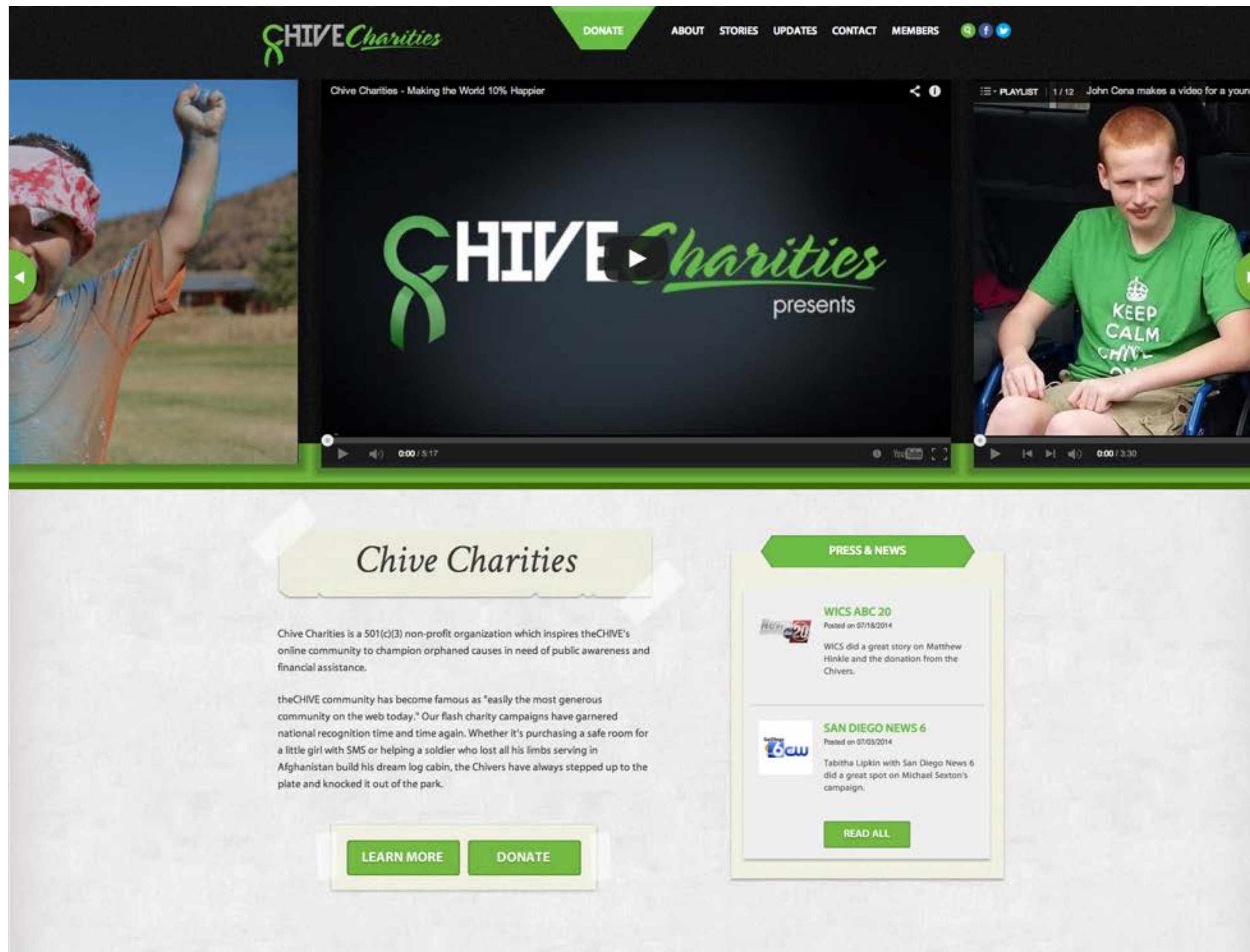
# openideo.com

The screenshot shows the OpenIDEO website homepage. At the top, there is a navigation bar with links for CHALLENGES, BLOG, COMMUNITY, HOW IT WORKS, and IMPACT. On the right side of the navigation bar, there are links for 'New here? Sign Up! or Login' and 'Connect' with social media icons for Facebook and Google+. Below the navigation bar is the OpenIDEO logo and the tagline 'Where people design better, together'. A search bar is located to the right of the logo. The main content area features a large white box with the text: 'OpenIDEO is an open innovation platform. Join our global community to solve big challenges for social good. [Sign up](#), [Login](#) or [Learn more](#)'. Below this is a featured challenge section titled 'FEATURED CHALLENGE' sponsored by 'The Clinton Global Initiative'. The challenge is 'How might we build better employment opportunities and pathways for young people around the world?'. It includes a video player with a play button, a description of the challenge, and a 'PARTICIPATE NOW' button. At the bottom, there are three smaller challenge cards: 'YOUTH MENTOR CHALLENGE PARTICIPATE NOW', 'How OpenIDEO works' (with a play button), and 'WOMEN'S SAFETY CHALLENGE CHECK OUT OUR FUNDED IDEAS'.

## ASPECTS WE LIKE

- Offers video content which typically receives a higher rate of engagement over static content
- Has the ability to register with a platform (Facebook and Google+) you are already active with or create a unique username and password
- Has a robust community

# chivecharities.org



## ASPECTS WE LIKE

- Offers video content which typically receives a higher rate of engagement over static content
- Includes personal stories
- Very visual

# nwfecoleaders.org

The screenshot shows the homepage of nwfecoleaders.org. At the top, there is a navigation bar with the NWF Wildlife Federation logo, the text "ECO LEADERS A COMMUNITY FOR STUDENT ENVIRONMENTAL LEADERS", and links for "LOG IN OR REGISTER" and "DONATE". Below this is a search bar and a main menu with items like "Home", "About", "Dashboard", "Forums", "Explore Projects", "Start a Project", "Earn Recognition", "Members", and "Beta Users". The main banner features a large image of people working on solar panels and holding protest signs, with the text "BECOME AN ECOLEADER Join with Others and Lead" and a "LEARN MORE" button. Below the banner are four orange buttons: "Learn About EcoProjects", "Connect with Others", and "Run your own project". On the right side, there is a login form with fields for "Username" and "Password", a "Remember my Email" checkbox, a "LOG IN" button, and a "Forgot your Password?" link. Below the login form is a "New to EcoLeaders?" section with a "SIGN UP TODAY!" button. At the bottom right, there is a section titled "This Community is For you if..." with social media icons and text describing the community's focus. On the left side, there is a vertical sidebar with social media icons for Facebook, Twitter, LinkedIn, Tumblr, Google+, YouTube, and Pinterest. The main content area below the banner features a "Featured EcoLeader" section for Sarah Minkin, a graduate student at Ohio University, with a photo and a detailed bio. Below this is a "Latest" section with two recent posts: one from goodlawmorisj and another from cochranc and chelseah.

## ASPECTS WE LIKE

- Has the ability to create your own profile, search users and view your own personal “dashboard”
- Includes the ability to share across a wide variety of platforms

# girlup.org

The screenshot shows the homepage of girlup.org. At the top left is the logo with the tagline "Uniting Girls to Change the World". To the right is a "join the movement" section with an email and zip code input field and a "SIGN UP" button. Further right are "quick links" for parents, educators, press, and shop, along with social media stats for Facebook (236k) and Twitter (1,289). A navigation bar contains buttons for "learn", "about", "blog", "take action", "clubs", and "donate". The main content area features a large banner for the "Girls Count Act Introduced in the Senate" with a "ACT NOW" button. Below this is a "we are 378,200 strong" section with a "sign up" button and a "get involved!" section with three sub-sections: "THE CHALLENGE", "THE SOLUTION", and "YOUR ROLE", each with a corresponding image and a "+" icon.

## ASPECTS WE LIKE

- Has clear calls to action
- Includes a variety of rich, dynamic content types including video, a blog and several ways to get involved

[we.care.org](http://we.care.org)

The screenshot shows the we.care.org website with a navigation bar at the top containing links for ABOUT, NEWSROOM, CONTACT, GET UPDATES, a search bar, and social media icons. Below the navigation bar are tabs for OUR WORK, EMERGENCIES, IMPACT, GET INVOLVED, and DONATE. A secondary navigation bar includes Home, Blogs, Connect, Explore, Learn, Attend, and My CARE. The main content area features a large image of a smiling woman on the left and a text block on the right titled "ADVOCACY" with the subtext "The CARE Action Network helps educate our nation's leaders about issues of global poverty. Join us!". Below this are two buttons: "POLICY & ADVOCACY BLOG" and "LEARN MORE".

The "Latest Notes From the Field" section contains two entries:

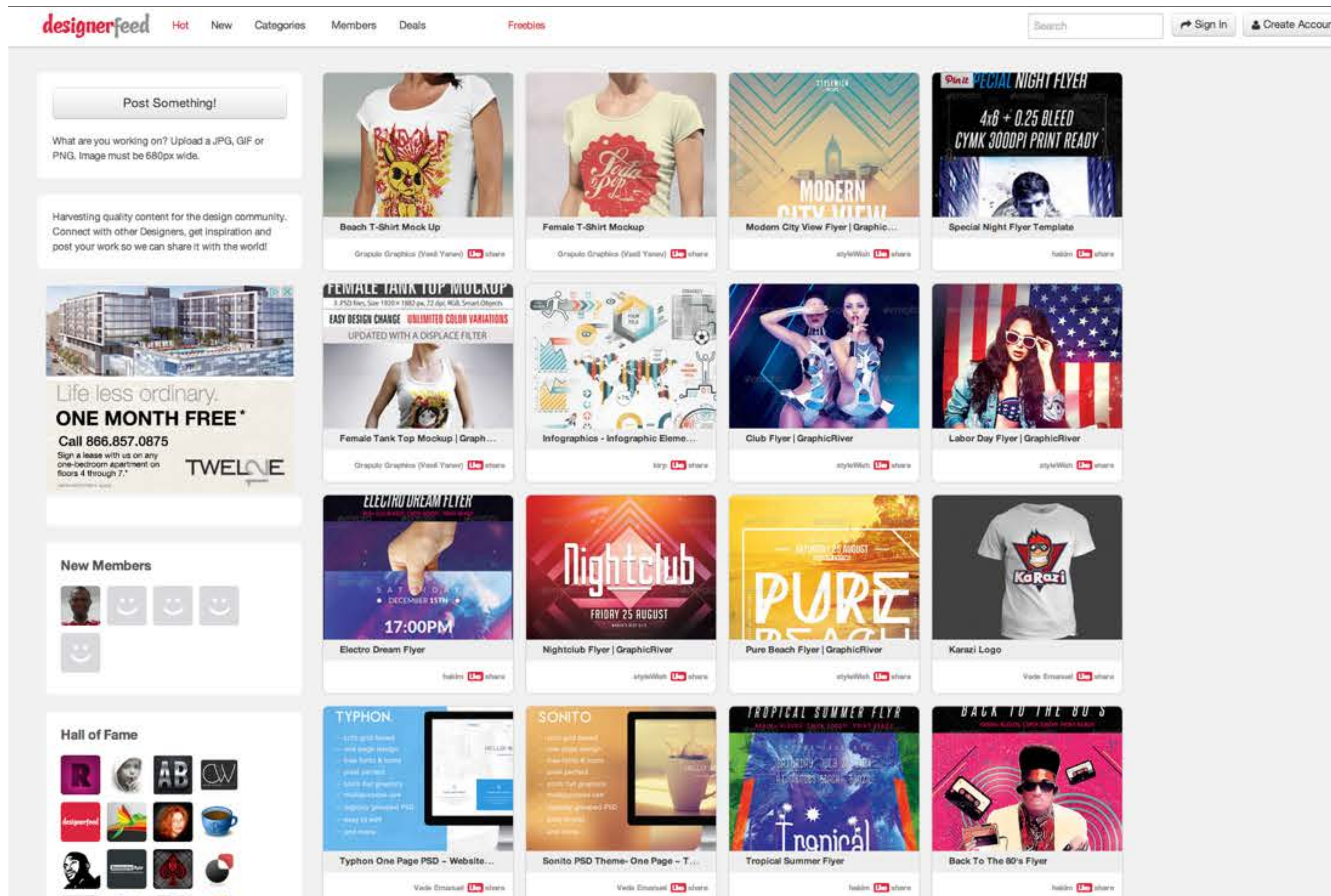
- Happy 66th Anniversary to Leo and Helga!**  
Sixty-six years ago, CARE played matchmaker for one amazing couple! CARE wishes a happy 66th wedding anniversary to the original CARE Package® couple, Helga and Leo Kissell. [more...](#)  
Posted by [kkrattan](#) on [Notes From the Field](#) Aug 7, 2014 10:53 AM EDT
- Crisis in West Bank and Gaza: "When they return, they will find nothing"**  
Haifa Abu Amro, CARE staffer in Gaza, 30 years old talks about how she has lived through the violence in Gaza and what she sees on the ground. [more...](#)  
Posted by [stfavo](#) on [Notes From the Field](#) Aug 5, 2014 4:03 PM EDT

At the bottom of the page, there is a "Log In or Join Now" section with input fields for Username and Password, a "Remember my email" checkbox, a "Forgot your password?" link, and "Join Now" and "Log In" buttons. Below this is a section for "Share with your friends:" with social media icons for Facebook, Twitter, LinkedIn, and Google+.

## ASPECTS WE LIKE

- Includes a variety of ways readers can become engaged from creating an account, joining a conversation or group, viewing video and photo galleries or reading the blog
- Members can sign up to receive updates

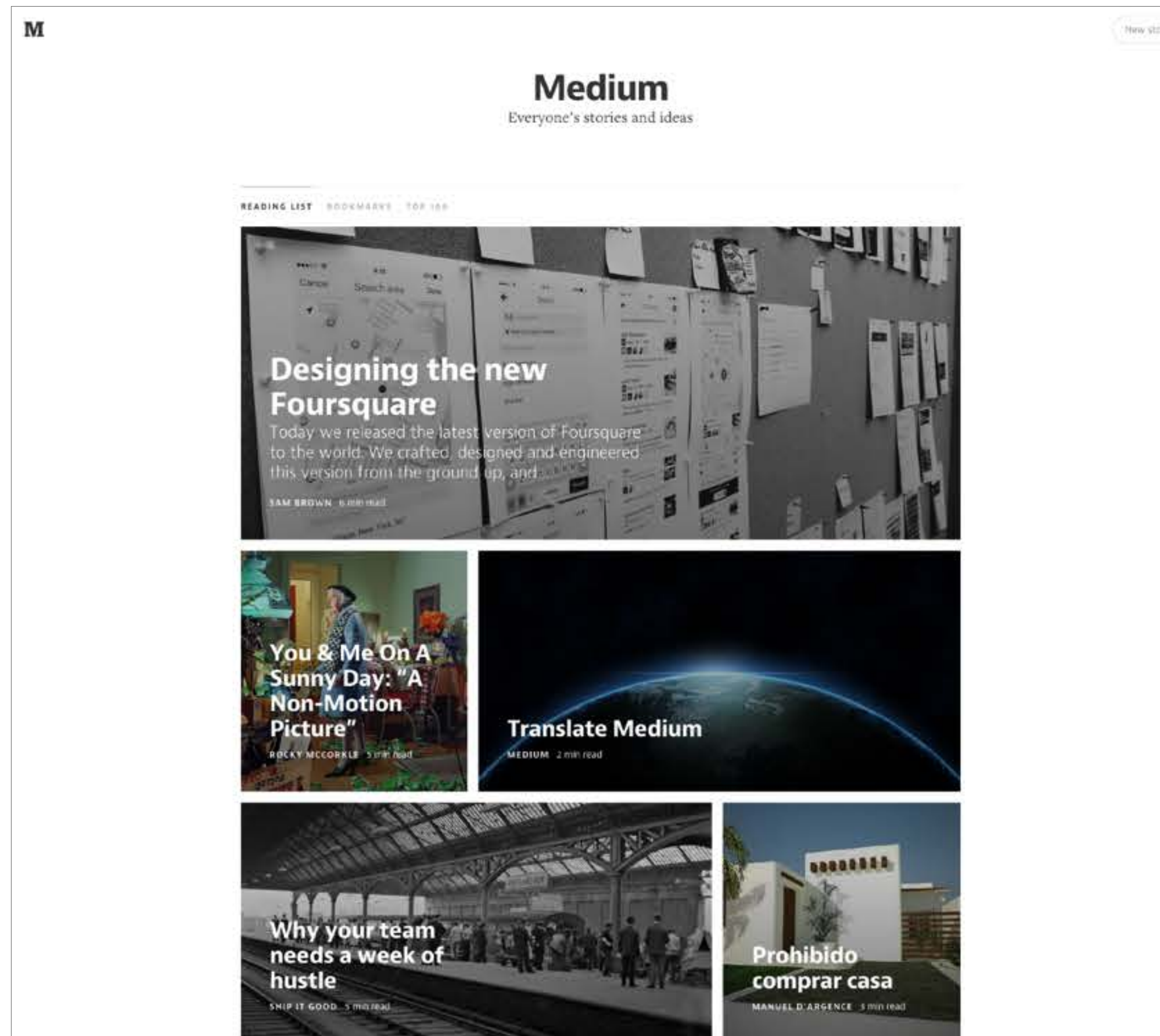
# designerfeed.com



## ASPECTS WE LIKE

- Very visual with strong use of imagery
- Showcases recent activity within the platform and pulls in recent activity from various outside social platforms
- Easy to use user interface
- Not only lists members but creates an incentive for members to register by having a "New Members" section and "Hall of Fame" section
- Content can easily be shared across a variety of social channels

# medium.com



## ASPECTS WE LIKE

- Allows you sign in through Facebook or Twitter
- Allows you to “Bookmark” stories
- Stories are presented in a highly visual fashion

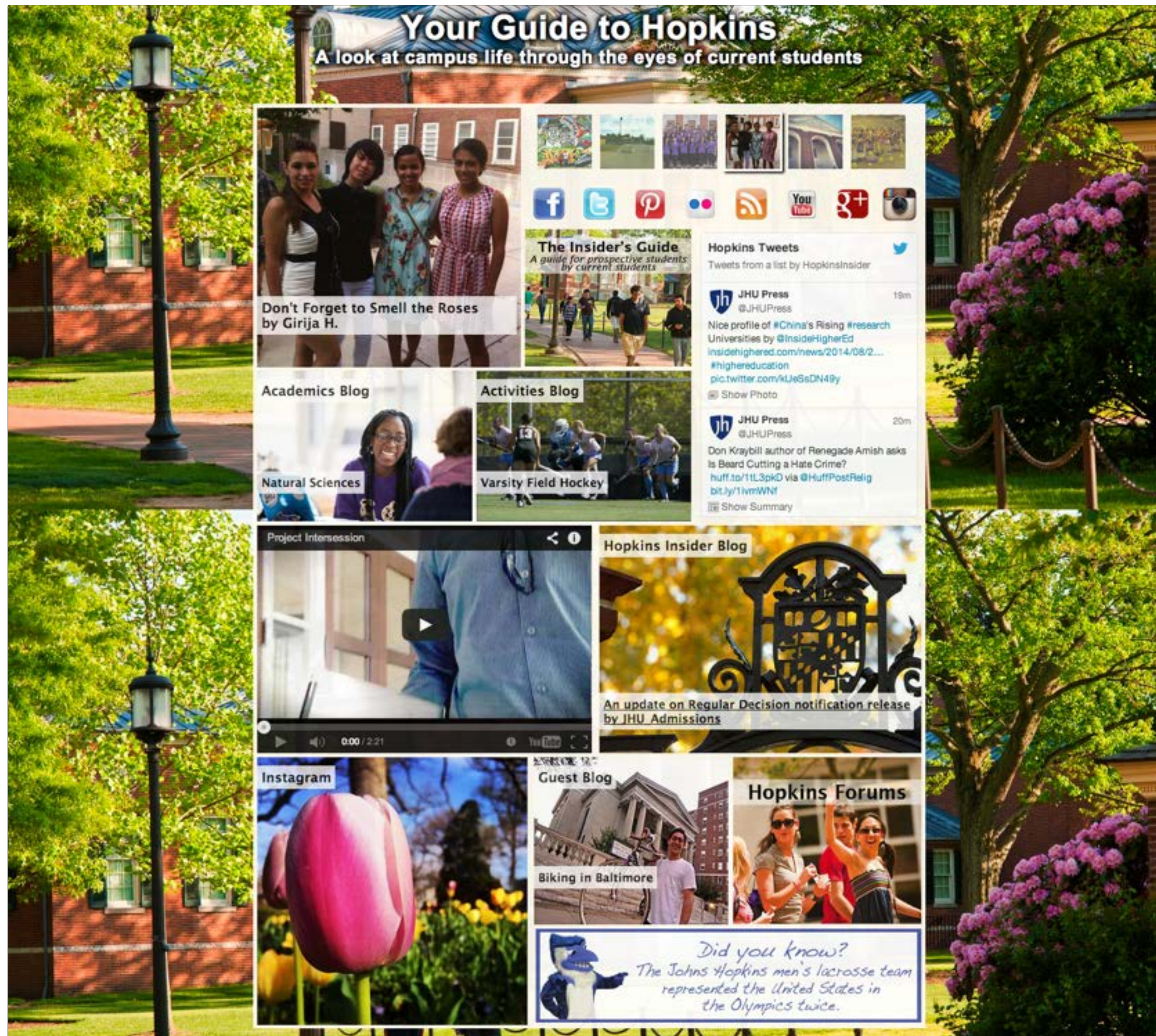
# [harvard.edu/social-media](http://harvard.edu/social-media)

The screenshot shows the Harvard University website's social media hub. At the top, there's a navigation bar with links for Apply, Faculty, Staff, Students, Alumni, Parents, Visitors, and Media, along with a search bar. Below this is the Harvard University logo and a menu with options like About Harvard, Admissions & Aid, Schools, and Resources & Offices. A secondary menu includes Gazette News, Events, Contact Harvard, The Harvard Campaign, and Give. The main content area is titled "Social Media" and includes a featured update about #Harvard2018 freshmen, a "Social Media Directory" with a search bar and a list of various university departments and centers, and a "Find Us on Facebook" section showing a grid of photos from the Harvard University Facebook page.

## ASPECTS WE LIKE

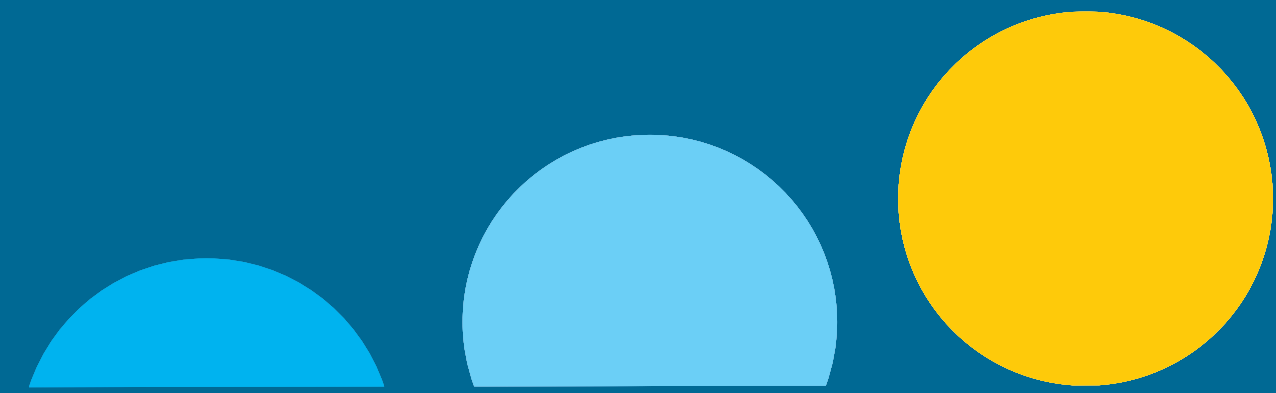
- Illustrates the concept of a social media mashup by having a single platform showcase all social media networks

# hopkins-interactive.com



## ASPECTS WE LIKE

- Content is entirely created by current Johns Hopkins students, specifically the members of the Student Admissions Advisory Board
- Volunteers represent the student voice of Johns Hopkins and are open and excited to share their experiences with interested, applying, admitted, and enrolling students
- Registration Agreement for the Forums is quite clear about conduct and suitable content



**CYSTIC FIBROSIS  
FOUNDATION**

**ADDING TOMORROWS**