Communications Plan

Messaging Foundations (from PR firm deck)

Purpose: To accelerate the development of treatments for accelerate. Our approach is to identify and fund projects that overcome critical barriers to successful drug development and to coordinate scientific efforts to improve efficiency and speed in the field.

Priorities: De-risking pre-clinical research and enabling collaboration

Communications Goals:

- Increase touchpoints with the patient/caregiver community, including younger families
- Expand financial support beyond the current donor base
- Amplify awareness of among researchers and the industry
- Strengthen collaboration/relationship with and keep relationships with other organizations strong

Recommended Strategies to Meet Communications Goals:

- Solidify Communications Infrastructure
- Focus on Key Moments
- Direct Audience Engagement

ANOTHER WAY TO THINK ABOUT THE ABOVE INFO:

Audiences: Your Communications Goals above are also a breakdown of your audiences. Each audience has needs and a level of investment you need to meet with your comms. Not every tactic and not every message applies to every audience. Your audiences are:

- Patient/caregiver community (with a focus on younger families)
- Potential donors (I'm assuming these are people outside the patient/caregiver community)
- Researchers/people in the medical field
- and other aligned organizations

<u>Action Areas:</u> These are the high-level buckets I'd recommend using to more easily keep track of the strategies and tactics recommended by your PR firm, which I'm fleshing out. Use these to think about your audience's different needs:

- **Brand awareness:** Getting the name and mission out there (most useful for your younger patient/caregiver families, potential donors, and researchers, but also might be useful for aligned organizations)
- **Thought-leadership:** Building an outward-facing reputation as experts in treatment, building trust and authority on this topic (most useful for researchers/medical field and aligned organizations, but also nice to have for potential donors audience)
- **Earned media:** Stories and news you pitch to publications and get placements for -- unpaid, placement is earned based on the newsworthiness of your pitch (most useful for researchers/medical field, young patient/caregiver families, and potential donors, but also might assist your reputation with aligned organizations)
- Contact/donation generation: Pursuing the collection of new contact info to build your reach and/or asking for donations after educating/engaging/adding value to an audience (most useful for potential donors and young patient/caregiver audiences)

Your PR firm did a good job uncovering the audiences and had a decent grasp on the action items, but I think categorizing these aspects in this way is easier to digest and remember on a day-to-day basis. These are the foundational building blocks not only of the following strategies but pretty much for all of your communications ever -- unless you dramatically shift your organization's mission.

Tactics Recommendations for Each Strategy

Strategy: Solidify Communications Infrastructure

- Create a pitch deck focused on 3-5 top things (topics) audiences should know about
 - o Topic 1: More clearly define overall mission (elevator pitch):
 - What's currently on your homepage: has a singular purpose: To accelerate the development of treatments for . Our approach is to identify and fund projects that overcome critical barriers to successful drug development and to coordinate scientific efforts to improve efficiency and speed in the field.

- How I would adjust this section on your homepage: is treatment-focused. We work to accelerate the development of treatments for it is is identifying and funding projects that overcome critical barriers to successful drug advancements and by coordinating scientific efforts, we connect patients and families to treatments with the highest potential to enhance quality of life.
- l've reworded this about section as an example of how you can be more direct and eye-catching about your mission while also tying in the human/emotional element of the impact on people living with
- - Also, tie in the human element here, especially for patients/caregivers/young families and potential donors. While I understand you're differentiating yourself from should still show and tell how the advancements in treatments can improve (or are improving) lives. The message is how to live with what's available, yours is how lives are improved by advancements and new options -- those messages can exist hand-in-hand.

I think #1 and #2 are your strongest messages and the ones to focus on if you need to be brief. I love the breakdown you have on your homepage's "Making Connections" section so I'm suggesting you use those 3 areas as your next 3 topics, but treat these as somewhat secondary. The first two can stand alone, these further flesh out to your audiences when you have more time/space for a message. (I'm wordsmithing these a bit but I like them a lot).

- Topic 3: Funding Breakthroughs: connects funding partners with researchers poised to drive advances in treatments for turn, breakthroughs in treatments for autism and other neurological diseases.
- Topic 4: Connecting Researchers: aligns scientists, investors, and companies around a unified strategy to accelerate the development of cures for
- Topic 5: Empower Treatment: connects patients and families living with a to prospective treatments with the highest potential to enhance their quality of life.

- Conduct SEO audit and implementation for
 - O I'm not an SEO expert, but there are scrappy ways to make yourself rank for searches around topics you'd like to. Hiring an SEO specialist is the way to really guarantee success here, but at the end of the day, Google rewards sites that are well-laid out and that offer relevant, helpful content to readers. If your site is set up to make a reader happy, Google should be happy too.
 - Your website could/should work for all of your audiences -- there should be pathways for each audience to get to content of interest. For example, I'd suggest making one of your main navigation tabs about patient/family stories to reach your patient/caregiver/young families audience. It's got some great videos on it but it's buried under the Strategic Priorities menu item (an item that sounds more appropriate for the researchers' audience).
- Assess and activate a social media scheduling tool (and schedule posts in advance, monitor it live at times, follow and engage with relevant accounts, find partnership opportunities, and create a content calendar in general)
 - I see the PR firm has suggested some platforms here which is good those can be worth the cost if you're willing to commit to a solid and
 consistent social media strategy. They help you post across multiple
 platforms and schedule posts in advance so you can work ahead and not
 be stressed about creating and posting something each day.
 - Unfortunately, platforms like Instagram and LinkedIn punish accounts that don't post on a consistent basis by not showing those posts at the top of followers' feeds. And Twitter might be the same way (honestly it's such an unpredictable mess of a space since it was bought).
 - I could see social media working best for you to reach the patient/caregivers/young families audience and the aligned organizations' audience.
 - There might also be ways to use Linkedin to boost your thought leadership (posting scientific articles, sharing medical conferences, having researchers you've worked with post about expect you'd be more likely to find researchers and decision-makers at aligned organizations on LI than any other social platform.
- Increase the collection of email addresses by providing opportunities and reasons for audience members to give their contact info
 - This will likely best tie into the content you create around topics #1 and #2.
 You will want to offer some kind of value for free (like the guide to existing treatments and treatments in development mentioned in topic #1) and

then provide a call to action to collect their name and email address - like your current newsletter form.

- If possible, have a web developer move that newsletter form to the footer of your site and have it appear in other places on your site like the end of blog posts or even in the hero rotator of your homepage. Reducing the amount of clicks to reach the form typically increases conversions.
- The ideas I've listed here are hopefully the easier ones to achieve but there are endless other ways to get more contact info we could brainstorm if you'd like. Events, webinars, special content, giveaways, etc. are all options.

Strategy: Focus on Key Moments

- Map out 2023 milestones/big moments to engage stakeholders focus on one or two moments per quarter to maximize content and messaging while maintaining some consistency (not jumping tracks on every communications touchpoint)
 - Milestone 1: Share a specific advancement recently made in a treatment path - focus on what it means, explain it in plain English for non-medical donors, and tell how further donations/support of will help it move forward.
 - Audience: Mainly patients/caregivers/young families and potential donors.
 - Message: Essentially to say "Look at the progress that's been made towards a treatment/cure/improvement of quality of life."
 - Channels: Web content like a blog post, email, social media, earned media (press release), video content, speaker spots at a medical conference,maybe even an event. Share and partner with or another aligned organization to get the message out.
 - Call to Action: Essentially "Let's keep this momentum going donate/get involved now"
 - Milestone 2: Share one of your family stories and feature that family for a time. Just like in the videos on your website, share the journey from diagnosis to the present day but also share any impact treatments have had (or that has had) to showcase why support for is important.
 - Audience: Mainly patients/caregivers/young families and potential donors. This could also be good to share with researchers and aligned organizations to remind them of the humans living with
 and the difference research makes/can make.

- Message: Essentially to say "this is what life with this is how one family is trying to combat it, and this is why your support makes a difference."
- Channels: Web content like a blog, social media, email, earned media (human interest story), video content, perhaps an event in the family's honor, maybe present their story as a case study at a research conference.
- Call to Action: Essentially "This is what life with a this is how and why research is important to families."
- Milestone 3: A potential research breakthrough or other avenue. This can be different from Milestone 1 because this breakthrough is still untested or unproven. The idea for this milestone is to share a possibly game-changing new treatment tactic that has some compelling thought or piece of evidence behind it but still needs more research and funding.
 - Audience: Mainly researchers and aligned organizations. This message could also be shared with patients/caregivers/young families and potential donors, but I think this milestone is a chance to build thought leadership among medical pros.
 - Message: Essentially "This is a new potential breakthrough we're excited about, this is why we're excited, but we need to keep working towards it."
 - Channels: Presentations at research conferences and medical pro meetups, email, video content, maybe a fundraising event, maybe earned media (press release about the potential new treatment), maybe also publishing whitepapers or research papers in conjunction with some researchers -- trying to get the name onto some scientific documentation.
 - Call to Action: Essentially "We can talk the talk when it comes to the science and development of treatments. Help us walk the walk by engaging with our ideas or donating time and resources to this research."
- Milestone 4: Feature an aligned organization as a partner. Use this as a small campaign to get brownie points with them by talking about their initiatives (and use this campaign to note how you're aligned and how you're different). It sounds like is the perfect organization to do a partner campaign with.
 - Audience: Researchers and potential donors. This could also be useful information for other aligned organizations (to plant the seed that they could also be partners) and patients/caregivers/young

- families to help them understand the broader landscape of organizations and how fits into the picture.
- Message: Essentially to reemphasize " is focused on research and treatment development, we enjoy working with X organization because they do X and this is how we work together."
- Channels: Web content like a partner webpage, social media, email, video content, maybe a joint event or webinar. Any tactics where you can get the other organization to help you create or distribute content would be a big win.
- Call to Action: Essentially "This is what
 X does, support us both to make an even bigger difference.
- Earned media ideas:
 - Awareness Day: Engage rare disease media and local media with a patient/caregiver story and interview availability. Include a CTA to your website where people can donate and sign up for emails.
 - Voice of the Patient Report: Reach out to the reporters who covered the with an update. The media list used is available (in the slide deck).
 - I think these are good ideas as well I noted milestones above that could be good for earned media pitches too. It just depends on what specific items you might choose to feature as each milestone.

Direct Audience Engagement

- Send quarterly updates to donors continuing to educate them on the effect
 AND treatments have on families and the impact their donations have on your work
 - Email would be great for this put together a quarterly report for patients/caregivers/young families and potential donors for each milestone, but focus on the human interest side of things.
 - Supplement these emails with social media and maybe even video content to share the news.
 - Email or webinars would be good for researchers to get quarterly updates on these milestones too, but tailor that messaging to the science behind each milestone.
- Share content from other relevant advocacy groups (mentioned more above) and ask those same organizations to share your content too make sure the content you ask them to share doesn't ask for donations.
 - I tied this in as a milestone above treat partner relations like short campaigns and create content around working with each partner and

- boost that content to the right people for a time, then cycle to boosting content around the next partner, on and on until circling back to sharing about partner #1 again.
- Use the Consortium to educate the industry on key information that's important to the patient community and spotlight researchers you know while meeting new researchers and adding them to your community.
 - I'm not 100% sure what this Consortium is (I'm guessing a research event). But you could have a PR pro coach your experts on posting to Linkedin, submitting quotes to reporters for stories (via sites like), and applying for speaking opportunities at various industry conferences.
 - Depending on what research experts you have access to, you can look into strategies for making them thought leaders.
 - Submit abstracts to conferences when they have open calls for papers and presenters. Those opportunities (and some networking with researchers and conference hosts) can get your people and name on stage in front of other researchers and aligned organizations for free. Plus you can then take the presentation and the fact you were on stage to go share with potential donors and all of your other audiences after the fact.
- Develop a medical meeting strategy and secure 3-4 speaking slots in 2023
 - Got ahead of this bullet tied it into the one above.
 - The last one I'll add: depending on your budget, you could also look into hosting your own research event or small conference. That would be a heavier lift but if you're looking to do something different, it's an idea.