We asked the KIF1A.ORG community to share their ideas to improve our organization and advance our mission. Together, we developed the 2020 Action Plan. This is not a comprehensive list of activities, but an outline of our priorities over the next year. Learn more about the new and expanded initiatives we’re focused on in 2020.

**Organization & Community**
- **Advisory Committees** | Gather feedback & make recommendations for organizational improvement
- **Teams** | Activate volunteers to implement activities that advance our mission
- **Representatives** | Family members representing KIF1A.ORG at the country/regional level
- **Affiliate Operations** | Register KIF1A.ORG in key countries

**Research & Treatment**
- **Path to Treatment** | Therapeutic development strategy to benefit this generation of KAND patients
- **KAND Research Hub** | Open science platform to enable KAND research collaboration
- **Communication** | Regular updates on research activities, progress, insights & results
- **Stakeholder Engagement** | Outreach to prospective & existing stakeholders to engage in research & clinical care efforts

**Family Support**
- **KIF1A.ORG Family Forum** | Private portal & discussion forum for KAND families
- **Newly Diagnosed Support** | Communication & resources to provide more support for newly diagnosed families
- **Family Connection** | Resources & processes to improve engagement & communication between families
- **Care for the Whole Family** | Supportive resources to strengthen the wellbeing of the whole family

**Fundraising & Advocacy**
- **KIF1A.ORG Fundraising** | Identify & pursue major funding opportunities & grow online giving
- **Family-Led Fundraising** | Resources, ideas & guidance for family-led fundraising efforts
- **Marketing & Communications** | Communication from the organization & tools for advocacy
- **Annual Events** | Key annual events that will activate the whole community

Last updated January 27, 2020
ORGANIZATION & COMMUNITY

Advisory Committees
Gather feedback & make recommendations for organizational improvement
- 7–9 members representing family voices with diverse backgrounds
- Led by a chairperson voted on by committee members
- Committees to launch in 2020:
  - Patient Advisory Committee
  - Family Support Advisory Committee
  - Fundraising & Advocacy Advisory Committee

Representatives
Family members representing KIF1A.ORG at the country/regional level
- Representatives designated by KIF1A.ORG to serve as a country/regional point of contact for local individuals or organizations interested in learning more about KIF1A.ORG
- Representatives are active members of the community & knowledgeable of the organization’s mission & activities
- Countries/regions to be determined

Teams
Activate volunteers to implement activities that advance our mission
- Varying number of members, led by Team Leader designated by KIF1A.ORG
- Teams to launch in 2020:
  - Community Engagement Team
  - Family Resources Team
  - Fundraising Team
  - Research Engagement Team
  - Marketing & Communications Team

Affiliate Operations
Register KIF1A.ORG in key countries
- Establish legal charity status in key countries to strengthen local fundraising & advocacy efforts
- Pilot country to launch in 2020: United Kingdom
- Additional countries to be considered

KIF1A.ORG 2020 ACTION PLAN
RESEARCH & TREATMENT

Path to Treatment
Therapeutic development strategy to benefit this generation of KAND patients
- Collaborate with researchers to update & clarify “Path to Treatment”
- Tools & resources needed
- Timeline & deliverables

KAND Research Hub
Open science platform to enable KAND research collaboration
- Digital platform for data sharing & discussion to avoid duplication of efforts & accelerate discovery
- Open to researchers & other scientists (e.g. data analysts) from around the world who are interested in advancing translational KIF & related research

Communication
Regular updates on research activities, progress, insights & results
- Monthly/Quarterly updates from KAND Research Network
- Literature for families & clinicians to improve patient care, developed in collaboration with researchers & clinicians
  o Recommended tests
  o Symptomatic treatment options

Stakeholder Engagement
Outreach to prospective & existing stakeholders to engage in research & clinical care efforts
- Identify & engage KIF & related researchers at institutions around the world
- Outreach to clinics & patient organizations to identify & support misdiagnosed or undiagnosed KAND patients
- Grow natural history study enrollment & engagement

Note: KIF1A.ORG continues to support research efforts that are not included in these organization activities. For a more detailed look at the research activities we support, view the Path to Treatment.
FAMILY SUPPORT

KIF1A.ORG Family Forum
Private portal & discussion forum for KAND families
- Establish family portal at KIF1A.ORG
  - Discussion forum
  - Resource library
  - Member profiles
  - Community groups (e.g. by geography, language, age, severity, etc.)

Newly Diagnosed Support
Communication & resources to provide more support for newly diagnosed families
- Newly Diagnosed Info Packet
- FAQ page
- Facilitated connections to other families (e.g., by geography, language, KAND symptoms)

Family Connection
Resources & processes to improve engagement & communication between families
- Variant List
- Family Directory/Map
- Family Forum Community Guidelines

Care for the Whole Family
Supportive resources to strengthen the wellbeing of the whole family
- Tailored resources for:
  - Parents
  - Siblings
  - Grandparents
  - Bereaved families
- Care Packages
  - Hospital stays
  - Bereaved families
FUNDRAISING & ADVOCACY

KIF1A.ORG Fundraising
Identify & pursue major funding opportunities & grow online giving
- Identify potential KIF1A.ORG donors (corporations, foundations, individuals, etc.) & pursue prospects that align with our organization & mission
- Activate the community to engage in online fundraising campaigns
- Expand fundraising through KIF1A.ORG merchandise

Family-Led Fundraising
Resources, ideas & guidance for family-led fundraising efforts
- Resources
  - Fundraising Toolkit
  - Fundraiser Playbooks
- 2020 Pledge: Individual goals set by families & supporters to raise funds to advance our mission & realize our Path to Treatment

Marketing & Communications
Communication from the organization & tools for advocacy
- Expand communication channels & tools:
  - e-newsletter
  - Blogging
  - Annual Report
- Advocacy Toolkit
  - Media Toolkit
  - Brand Guidelines
  - Digital Assets
- Call to Action video

Annual Events
Key annual events that will activate the whole community
- Fundraising & advocacy activities on a global & local scale
  - Rare Disease Day – February 29
  - KIF1A Day – April 28
  - Giving Tuesday – December 1

KIF1A.ORG 2020 ACTION PLAN