



2020 ACTION PLAN

KIF1A.ORG

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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



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

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

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

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

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

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](#).

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
 - Recommended tests
 - 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

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
- KAND Conference – Tentatively scheduled June 26–28, 2020 in New York