Governance:

The volunteer board of directors of nine positions was strengthened by two new members: one is a father of a PKU child and VP of a major chartered bank and the other an adult with PKU who is a francophone, works in digital media and initiated a PKU blog on French-language social media. The first new director took on a role as Board Secretary and the second as lead for francophone matters. There were no changes to bylaws.

Management:

Remained stable with the same individuals continuing to serve as President, Vice-President and Treasurer.

Finances:

Non-profit remains solvent and its moderate level of activities are mostly volunteer-based. Please look to financial reports for a further breakdown of our financial records.

Direct Services:

We continued the typical round of five regional meetings, including our annual weekend camp in Ontario and the introduction of the same in the Prairies. These events allow for family and patient education, peer support and social networking - important for a community of a rare disorder spread across +7,000 kilometres, ten provinces, three territories and six time zones.

A cadre of volunteers led by our President continued to promote awareness of likely eligibility for the Disability Tax Credit and follow-on benefits. This sometimes involves direct case work with families and adult patients unfamiliar with the DTC criteria and sometimes hesitant to interact with the Canada Revenue Agency.

Another team of volunteers led by our Vice President assembled and helped distribute through clinics the highly-regarded PKU Starter Kits which help both families of a newly-diagnosed newborn and adult patients returning to clinical care.

Through a toll-free nation-wide telephone number we continued to respond to individual requests for information and guidance, including students doing school projects related to PKU.

Value-Add Education:

The President and Vice President took part in professional development conferences of scientific and health care professionals as well as patient organizations, including taking part in meetings of the Canadian Organization for Rare Disorders and the Best Medicines Coalition.

Memberships:

Continued on a pace of moderate growth.

Sponsorships

Our sponsorship continues to stay steady. Gold sponsorship comes from BiOMARIN however the contribution level has been reduced to a lower level. Silver Sponsorship comes from Cambrooke, Innovative Medicine and Nutricia. Bronze Sponsorship comes from Innomar Strategies, Modality Rx, Synlogics and Vitaflo. We received "In Kind" sponsorship from The Specialty Food Shop and StarFrit. We continue to look for new sponsorship opportunities as we move forward.