BDSRA foundation
Batten Disease Support + Research + Advocacy

PO Box 30049
Gahanna, Ohio 43230
(800) 448-4570

Joint Statement to our Worldwide Batten Community

As part of its third-quarter earnings release on Wednesday, November 8, 2023, REGENXBIO announced a corporate restructuring that included the difficult decision to halt the development of multiple potential AAV gene therapies, including the RGX-181 and RGX-381 programs for the treatment of central nervous system (CNS) and ocular manifestations of CLN2 Batten disease, respectively.

As collaborative patient advocacy groups who together are working to support, advocate, and raise funds for research for our Batten disease communities worldwide, we are heartbroken over this decision. We know the Batten community has faced devastating news like this numerous times in the past two years, predominantly due to the challenging global economic market which has had particularly detrimental impacts on the biotechnology sector.

In a letter to the Batten community, REGENXBIO has assured that it will be actively exploring partnership opportunities to enable the continuing development of its CLN2 gene therapy programs. It has also advised that the small number of patients who have already received a one-time dose in the clinical studies of RGX-181 and RGX-381 will continue to be followed and that those families have already been contacted and informed of these unfortunate developments.

We know this is difficult news for our Batten community. However, through our international collaboration as patient advocacy groups, we remain united, driven, and relentless in our pursuit of a world without Batten disease.

We wish to assure you that we are committed to working with REGENXBIO and their potential partners to ensure these programs advance. We will continue to provide relevant updates as they are made available. In the meantime, if you have any questions or concerns, please reach out to any of our organizations and/or REGENXBIO Patient Advocacy at cln2@regenxbio.com.

BDSRA foundation
BATTEN DISEASE Support and Research Association AUSTRALIA
BATTEN DISEASE Support and Research Association CANADA
Život Udruženje građana za borbu protiv retkih bolesti kod dece