

Association Monégasque contre les Myopathies / Only Project Governance and Transparency update

1. Context

Association Monégasque contre les Myopathies (AMM) was founded in 2001 by a group of parents with one priority: find a cure to Duchenne muscular dystrophy, following the diagnosis of their sons, Paul and Philippe.

Thanks to Only Watch, the unique watches charity auction, AMM has raised approximately CHF/€100M and funded very substantial scientific and medical progress, leading to a phase 1 clinical trial of a proprietary molecule currently taking place in France with 12 patients.

With sums raised growing and reaching records, the association remained small and agile, with no permanent staff, relied on a stable governance with a small board composed mainly of parents, and did not change its ways of functioning (allowing it to maintain functioning expenses around 1% and to act fast) ; the spirit being to rely on person-to-person trust, a lot of *pro bono* work and a profound determination to find a therapy for loved ones at home for whom the clock was ticking.

A few days before the 10th edition of the auction, questions were raised by onlookers about the governance and transparency practices of the charity organization, AMM, at the benefit of which Only Watch is organized.

Since then...

2. What we have already done in terms of advancing transparency

- ✓ **We shared documents giving detailed insights on the use of funds and the absence of any personal enrichment by members of the association.**
 - [Insights on how funds are allocated](#) including our detailed financial statements of the past 5 years, 2018-2022 (period over which 70% of funds were raised) with an [activities highlight document, year by year](#), all shared on our website;
 - Financial statements [2018](#)
 - Financial statements [2018-2019](#)
 - Financial statements [2019-2020](#)
 - Financial statements [2020-2021](#)
 - Financial statements [2021-2022](#)
 - A detailed list of [projects supported for the past 10 years](#) with names, institutions, amounts transferred;

- A [bank statement on the charity's current situation](#), showing than a bit more than half of funds raised since 2005 are on the AMM's accounts, kept to be able to face the next steps of current and future clinical developments;
- The financial statements of the two biotechs supported by the charity:
 - SQY Therapeutics ([2017](#), [2018](#), [2019](#), [2020](#), [2021](#), [2022](#));
 - Synthena AG ([2017](#), [2018](#), [2019](#), [2020](#), [2021](#), [2022](#)).
- ✓ As planned, **we changed the shareholder structure of our biotech SQY Therapeutics** (main recipient of the charity's funds in the past years and sponsor of the ongoing [clinical trial](#)) to have it entirely owned by the charity associations involved and ended the temporary situation (in which 6 members of families of patients owned 51% of shares) that allowed the company to save about €1M thanks to a French state program. During this period, no dividends were distributed as stated by the [certificate by the auditor from BDO](#) that was shared.
- ✓ **We developed and launched, in June 2023, a whole website dedicated to presenting the research projects** supported by Only Watch funds: onlyproject.org.
- ✓ **Answered all questions from our partners and media in the most detailed way to shed light on these different topics** and give more context to counter a "narrative" that was developed online by a few and that was not supported by any tangible evidence, suggesting that the charity had misplaced the funds. (We have made moves to request an **official right of reply** on articles spreading rumors and contributing to misinformation about our commitment and the Only Watch project.)

3. What we will do in the future to strengthen our governance and disclosure practices

We will continue to strengthen the organization of the association and make certified accounts available to the public in order to put an end to rumors and continue to focus our energy on finding a therapeutic solution for sick children.

More specifically:

- ✓ Have our **financial statements audited by a certified auditor starting with 2023** statements and share them online in the first trimester of 2024.
- ✓ Continue to feed and develop the onlyproject.org website to keep our community informed on the progress of research.
- ✓ Strengthen our governance by **integrating new profiles to the board of directors** and creating a **more formal scientific consultative board** featuring international profiles renowned for their expertise on neuromuscular diseases and DMD.

- ✓ **Create an annual report** presenting the certified accounts, the new governance and a progress report on the projects funded. We will be giving a greater say to those who run our projects and the people who benefit from it.
- ✓ Set up a **charter for the prevention and management of conflicts of interest**.
- ✓ Continue to take steps to **find innovative ways to host our biotech's potential profitability (intellectual property) into a foundation/non-profit organization**.

We are taking actions and measures to ensure our processes and transparency are aligned with the level of impact our charity organization has had and will hopefully continue to have thanks to you all.

As a result, the charity's functioning expenses will necessarily increase beyond the current 1 to 2%, but we are happy to take these steps to give our structure the maturity and transparency this unique project deserves. We understand that this is an essential move to enable us to continue to grow Only Watch and fund research for the benefit of DMD boys, men and their families.

In this process, we will do everything to preserve our key values and principles to date, namely:

- **Sobriety** in terms of functioning expenses;
- Being an **independent, agile, and efficient** supporter for researchers;
- Careful budget planning to be a 100% **reliable** partner in the clinical development;
- A tenacious belief in the power of **collaboration**;
- And more than anything **our determination to reach our goal: find a cure to Duchenne muscular dystrophy**.

It will take means and time, but this is a new chapter of our history that we are eager to move forward on.