Fédération des malades drépanocytaires et thalassémiques SOS Globi
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Créteil, le 7 janvier 2022

To Mister Andrew Obenstein and to whom it may concern within Bluebirdbio

We have well received your email, few months after announcing the withdrawal of your company, Bluebirdbio from the european market. We have read your communications and explanations but we still do not understand why this decision has been made.

Indeed, as you might have been aware, our organization has been involved in the evaluation of Zynteglo by the French HAS authority and was following with high interest the ongoing negociations between your company and the French health authorities to provide access to Zynteglo to bêta-thalassemia patients in France.
We also understood that, before any agreement had been found with the French authorities -and though discussions were progressing in a positive way -you decided to close the European market, leaving French and other European patients without an option to access a potentially life saving therapy.
We found it highly disrespectful and cruel to the patients, their families, the healthcare professionals and the health authorities which supported development and advancement for market authorization of this innovative therapy.
We don't really understand why, if it isn't for profit reasons, regardless of the patients' interests, you decided not to proceed further and to end up the negociation journey in France while it could have been successful and opened access to the patients.
We would like to highlight that as a patient advocacy group, we firmly condemn this type of behaviour which raise great doubts about the real interest of Bluebirdbio for patients. Needless to note that Bluebirdbio's attitude might have heavy consequences for patients in the future in making the regulatory processes in Europe heavier and thus delaying access to other potentially life saving treatments.
Additionnaly, the trust that we had in collaboration with pharma companies such as the one that existed between your company, Healthcare professionals , Health Authorities and patients' organizations will suffer this precedent.

As patients' representatives, we are calling for a better regulation of the authorization process that will oblige industries to commit to provide a treatment to patients as soon as the evaluation of the HAS is provided, regardless of the pricing negociations.

Kind Regards

La Présidente, Maryannick LEPETIT