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罕病龐貝氏症治療照護進階 賽諾菲攜手病友、專家與法國工商會同慶

【新聞稿】



賽諾菲於 4 月 22 日舉辦罕見疾病龐貝氏症(Pompe disease)創新治療健保給付會議, 有國內 95 名龐貝氏症照護專家實體或視訊與會,並邀請龐貝氏症病友與照顧者、法國工商 會(CCI French Taiwan)代表蒞臨開幕式,慶祝台灣龐貝氏症治療照護進階。

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賽諾菲罕病事業處處長奧利(Olivier FILICIC)指出, 龐貝氏症是一種罕見、漸進性且致命的肌肉疾病。日前他參與台灣龐貝氏症協會舉辦的國際龐貝氏症日活動, 深受病友的生命故事感動與鼓舞。



龐貝氏症病友與家屬也在開幕式分享疾病歷程與治療經驗,確診龐貝氏症後歷經情緒低
落沮喪,之後勇敢面對積極治療與復健;病友也感謝醫護人員的照顧與創新治療的研發,提
供更好的照顧品質,也期盼創新治療幫助更多病友。

賽諾菲在台灣深耕近 40 年,致力於追求更好的罕病照顧(Better Care for Rare),協助 全台約 70 家醫療院所強化新生兒與高風險篩檢,提高病人接受創新治療的可近性,以及提 供整合支持照護服務,許罕病病友一個美好的未來。

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法國工商會理事長白志堅(Benjamin LAMBERG)在開幕致詞時表示,法國與台灣是策略 夥伴關係,台法合作會持續強化。法國工商會在台灣相當活耀,有超過 200 個會員,涵蓋 精品業、航空業、工業、電子半導體、能源等;賽諾菲是法國最大、全球領先的藥廠,更是 創新治療的領導者,替罕病、血友病、糖尿病、心血管疾病患者提供治療照護服務,並提供 疫苗保障民眾健康。

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(English version)

Sanofi hosted a launch event of advanced treatment for Pompe disease on April 22, 2023. We welcomed 95 healthcare professionals for Pompe disease care joined on-site or virtually. Patients with Pompe disease, their caregivers and the CCI French Taiwan representative were invited to the opening session to celebrate the launch.

Olivier FILICIC, Head of Rare Disease of Sanofi Taiwan, shared that Pompe disease is a rare, progressive, and life-threatening muscle disorder. He was invited to the International Pompe Day event hosted by Taiwan Pompe Association and was deeply touched and encouraged by patient story.

In the opening session, patients and caregiver shared their journey with Pompe disease. They felt depressed when getting diagnosed with Pompe disease, but still faced it with courage, treating and rehabilitating actively. They appreciated HCPs' efforts and development of the advanced treatment, providing better care to them, expecting the advanced treatment benefits more patients.

Sanofi has cultivated in Taiwan for nearly 40 years and committed to the pursuit of better care for rare. We've supported about 70 hospitals to strengthen their newborn and high-risk screening. Also, we are dedicated to increasing patient access to innovative treatment and providing integrated support along the patient journey as well. Sanofi' s mission remains clear: we strive to enable fulfilling futures for extraordinary people, no matter how rare their condition.

Benjamin LAMBERG, the chairman of CCIFT, was proud to present that France as an important strategic partner of Taiwan, and the cooperation between our two countries is very strong and will get stronger. CCIFT have more than 200 members, include luxury, aviation, industry, electronics and semiconductors, energy etc. Sanofi is one of its industrial gems of France. A global market leader – but more importantly an innovative leader providing care for rare disease, hemophilia, diabetes, and cardiovascular diseases, and provide vaccines for prevention.