

THE JEROEN PIT HOUSE



A new transition house for serious ill children and their parents

"You dream of being home again, all together as a family, but how do you get the care sorted that you need at home? Is it even possible? Soon things will get worse, much worse ... "

THE PROBLEM: THE STEP FROM HOSPITAL TO HOME

Seriously ill children often stay in hospital for long periods of time because, due to the nature of their illness, they are dependent on high-quality medical and nursing care 24/7. This concerns an increasing number of children with complex chronic illnesses such as degenerative muscle diseases, metabolic disorders, chronic renal failure, heart defects, (acquired) paralysis or difficult-to-treat epilepsy. However, these children are best cared for at home. There, they develop better and they are better bonded with the family, which means their quality of life is better than in the hospital. It's a quality of life to which every child is entitled.

As soon as seriously ill children are no longer under the supervision of a doctor 24/7, the family wants to go home. Yet, it is often extremely complex for these children to be able to safely and securely make the step home. It is a huge transition. Parents have to deliver and organize the complicated and intensive home care themselves both day and night. In addition, they often have to manage a whole team of care providers and be able to deal with numerous practical and administrative issues. On top of all this comes the household upkeep, work and care for the rest of the family. An enormous load that involves many uncertainties and stress and therefore has a huge impact on each family member. Within the family, this often leads to psychological, social, financial or relational issues, and it is not uncommon for parents to overlook the care of their child. Hospital admissions and frequent visits to the emergency room can be the result and this, again, is very troublesome and disruptive for the sick child, the family and the healthcare system, in general.

THE SOLUTION: A NEW HEALTHCARE CONCEPT IN A NEW BUILDING

The aim of The Jeroen Pit House is to make the transition to home for children and parents easier, safer and steadier. To this end, it must become a facility where parents can learn to deal with the complex, intensive and often technical care of their child in a safe family-friendly environment. In addition, parents must become as self-reliant as possible with regard to everything that is involved in home care for a child with a chronically complex disorder. To accomplish this, a wide range of high-quality care and guidance will be offered to all family members in The Jeroen Pit House. In addition to medical and nursing care, this also includes psychosocial, social and practical support. With the transition to the home situation in mind, there will also be close collaboration with home nurses, youth care, general practitioner and municipality and the social network of the family will be involved as much as possible.



The Jeroen Pit House will be an independent, new, care accommodation on the grounds of Amsterdam University Medical Centre, location AMC. The house will be built in the middle of the Health Park, in a green environment with lots of light, space and with a direct view of nature. A warm, homey feeling with abundant privacy is paramount. There will be eight family apartments each with a room for the sick child, a living room with pantry and a bedroom for parents and brothers or sisters. In addition, The Jeroen Pit House has a number of central facilities: a large family kitchen, a cozy living space, sports, meditative, or 'chill' space, rehabilitation facilities and a private garden.

The care in The Jeroen Pit House is aimed at both the child and its family, so that the transition home can take place in a as safe and, above all, as stable way as possible. The Jeroen Pit House is, therefore, a physical home, but beyond that, a new care concept, focused on family empowerment. The ambition is to roll out this care concept nationally in the long term by setting up a branch at several academic medical centers. The Amsterdam branch will act as an expertise center for this, among other things, by implementing extensive scientific research and evaluation with continuous improvement of the care model.

ORGANIZATION AND PLANNING

The Jeroen Pit House project is an initiative from Amsterdam University Medical Centre, VanKarnebeek4Kids Foundation and Lindenhofje, a nursing childcare home from the Salvation Army. These parties have formed a project team with a number of working groups. Supported by a knowledgeable and broadly-oriented Advisory Board, they provide direction for the realization of The Jeroen Pit House. Various well-known parties also cooperate in this project phase by offering their services pro bono.

The Jeroen Pit House will be managed by the independent Foundation, "Stichting Jeroen Pit Huis". This foundation will receive the building "free of charge" from the separate foundation "Stichting Vrienden van Het Jeroen Pit Huis". This organization will take care of the building and (permanent) interior of the house and, thereby, be the owner of "the bricks". The funds that are raised for The Jeroen Pit House will be transferred to the Friends of The Jeroen Pit House Foundation through a fund in the name of Stichting Steun Emma Kinderziekenhuis. The remaining part will go directly to the operating foundation to finance the costs of the (separate) establishment.

The go-decision on the realization of the Jeroen Pit House has been made by the project partners in March of this year and the building preparations are in full swing. If all goes according to plan the construction can commence in the beginning of 2021 and the house can open its doors in the first quarter of 2022.

STRUCTURAL COSTS & FINANCING FROM ONE-TIME

The annual healthcare costs of The Jeroen Pit House will largely fall under the Health Insurance Act. Agreements on this have been made with health insurers. A small part (10%) of the exploitation costs – the stay of the parents in the Jeroen Pit House- are at this moment not covered by the healthcare law. The Ministry of Health, Welfare and Sport and the Care Institute have officially confirmed to subsidize the additional costs for the stay of the parents for a period of 3 years. In the meantime they will develop, together with Care institute Netherlands and Dutch Association of Pediatrics, a new care guideline for family oriented transition care. These guidelines will describe the criteria that are needed for this type of care and under which conditions the stay of the parents is necessary. On this basis, the stay of the parents will in due course also fall under the health insurance act and thus be financed by health insurers.

The one-off project costs of The Jeroen Pit House amount to €1.2 million and are borne by the project partners. The Amsterdam UMC is providing the building land free of charge.

The VanKarnebeek4Kids Foundation, supported by Stichting Steun Emma Kinderziekenhuis (The Support Emma Childrens Hospital Foundation), has taken on the responsibility to raise the funds for the construction of The Jeroen Pit House. This required an amount of at least € 7 million. The heirs of Jeroen Pit, who died to young in 2012, have confirmed a donation of € 3,5 million. In addition, € 4.15 million in funds has been pledged in a short period of time by a select group of private parties, companies and foundations. On the basis of these commitments among other things, the project partners were able to take the decision last March to start preparations for construction. However, there are still a number of ambitions and important services needed for the house, the seriously ill children and their families, for which the financing is not complete. This still requires an amount of approximately € 0,35 million. www.hetjeroenpithuis.nl