



SUPERBEADS World's most important beads

The treatment of children's cancer is often long and hard. To support and encourage children and young people on this difficult journey, Barncancerfonden Västra presents "**Superbeads**"

Children receive a superbead for every x-ray, blood test, hospital visit, injections etc. Each treatment has its own specific colorful bead. These Superbeads are added on a string and together they tell the unique story of the child's treatment path.

A few days after diagnosis each child receives a waxed string with an anchor and letter beads forming his or her first name. Following this the patients receive new beads for each treatment so they can record, tell and own their story.

Superbeads purpose

Although the Superbeads can be something children look forward to during hard times it is much more than just a fun collection of beads.

The personal string of beads create a colorful picture of a difficult period that is often abstract and therefore difficult to put into words for the patients. Superbeads give children a better understanding of each stage of their treatment; they get a concrete overview of what has happened. Each patient can fully verbalize his or her treatment/progress by following the story the beads create - every moment in chronological order from diagnosis to hospital visits, x-ray, stem cell harvesting, etc., etc.

If the child is very young during treatment the Superbeads can show them what has happened when they get older. When treatment is over the children and their families have the Superbeads as a colourful informative string of beads to keep and cherish.

How does it work?

All children and young people aged 0-18 that are treated can get Superbeads for free. Staff helps patients and caregivers to learn which bead represents which treatment. After this the patients or their caregivers should ask for the beads they have earned. When treatment is completed the Superbeads are finished with a special bead; no beads are handed out for follow-up consultations.

www.supersnöret.se

Copyright: Vereniging 'Ouders, Kinderen en Kanker' (VOKK)
Schouwstede 2B, Nieuwegein, the Netherlands.



Alphabet Beads: When treatment starts, the patient gets beads with letters representing his or her name.

Bead of hope: This bead signifies the beginning of this journey (Hoppets pärla)

Hair loss: When hair starts to fall or if one shaves it off (Tappa håret)

A super day: An extraordinarily positive occurrence is a super duper day (En superbra dag)

A really bad day: A difficult treatment or just a downright awful day (En mycket dålig dag)

Birthday: On your birthday (Födelsedag)

Single injections or needles: One injection or poke in a day (Stick/injektion)

Multiple injections or needles: More than one injection or poke on the same day (Flera stick på en dag)

Intravenous needles: Every time a needle is placed in a port-a-cath or a rickhamreservoir (Sätta venportnål)

X-ray/ultrasound: For every examination e.g. CT, MRI, ultrasound, imaging procedure (Röntgen/ultrasound)

Bone marrow (punctures): For every treatment that involves aspiration of bone marrow from hip bones (Benmärgspunktion)

Lumber puncture: For every lumber puncture performed (Lumbal punktion)

First intravenous cytostatic (Gold) medication: After the first treatment, intravenous or intrathecal of chemotherapy agents (Cytostatika/ Guldmedicin intravenöst eller intratekalt)

Continued intravenous cytostatic (Gold) medication: After each treatment, intravenous or intrathecal of chemotherapy agents (Cytostatika/Guldmedicin intravenöst eller intratekalt)

Cytostatic tablets: After every week of chemotherapy tablets (Cytostatika tablett)

First radiation therapy: For the very first treatment of ionizing radiation to treat a tumor (Strålning)

Radiation therapy continued: For all treatments after the first treatment (Strålning)

Radiation treatment mask: When a patient makes a treatment mask (Strålningsmask)

Surgery: For every surgery e.g. central vein catheter insertion, PEG feeding tube etc (Operation)

Cortisone: One for every period of cortisone (or one every day when patient takes tablets orally and needs encouragement) (Kortison)

Harvesting stem cells: For every harvesting of stem cells (Skörda stamceller)

Stem cells and bone marrow transplant: After receiving bone marrow or stem cell transplant (Stamcells och benmärgstransplantation)

Stem cells and bone marrow transplant: When patient gets out of isolation after the transplant (Stamcells och benmärgstransplantation)

Hospitalization: One for every hospitalization plus one for each started week during a longer stay (Inlagd på sjukhus)

Hospitalization in the intensive care unit: One for every admission to the ICU plus one for each started week during a longer stay (Inlagd på intensiv)

Acute hospitalization: When a patient needs to arrive at the hospital in an ambulance or on an emergency basis e.g. a high fever (Akut inlagd på sjukhuset)

Hospitalized in isolation: For patients who overnights in isolation and one for each started week in isolation (Inlagd och isolerad)

Feeding tube: For every time a patient gets a feeding tube inserted (Sondslang)

Blood transfusion: For every transfusion of a blood product e.g. platelets, red cells, plasma (Blodtransfusion)

Sutures and intravenous needles removal: Every time a patient has stitches or intravenous needles removed, or large plaster casts and other large dressings removal e.g. CVC bandage renewal (Ta bort stygn eller venportsnål)

Eye drops: For every day of treatment with eye drops (Ögondroppar)

Pre op shower: A bead for every anti-bacterial double shower pre ops (Dubbelbad)

Catheterization or enema: Every time patient gets a catheterization or an enema (Kateterisering eller lavemang)

Treatment over: After the last treatment (Behandlingens slut)