Beware and understand childhood cancer at early stage
This book titled “Beware and Understand Childhood Cancer at Early Stage”

in order to complete childhood cancer educational program, which is one of the programs of YAI. For the purpose of education of childhood cancer, this book is equipped with medical terminology associated with cancer, explained in simple terms so that general public could understand.

This book also listed the hospital names in Indonesia that cater for childhood cancer. The aim is to facilitate people in bringing their children suspected of having cancer to be further examined and treated accordingly.

May this book could bring benefit to the general public, especially the parents. It is our hope that this book could be a reference to save childhood cancer patients in Indonesia.

Warmest regards,
Yayasan Anyo Indonesia

*This book is free and not for sale*

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A couple brought their child to a doctor. They complained about a mass in the child’s neck. After conducting a series of examination, finally the doctor determined that the child has a tumor and recommend for further examination.

The husband and wife immediately felt like their world has ended. This is the reality in our community today. Would it not be understandable should we react like the above couple once we heard that our beloved child suffered tumor?

The above incident happened since general public does not understand the true definition of tumor and cancer. According to medical dictionary, tumor is a mass. For example: a child hit his head on the border of his bed and suffered bruise. The mass in the head of the child is also categorized as tumor.

There is non-malignant and malignant tumor or mass. The party who can define whether a tumor is malignant or not is an anatomy pathologist specialist.

If malignant, then the said tumor or mass can be categorized as cancer. In other words, cancer is a tumor or mass that are malignant.

Microscopically, cancer is a group of cell not bound by capsule. As a result, these cancer cells would easily spread out to other parts of body outside of the affected area. This is why cancer is known as malignant.

For example: a child with eye cancer. Logically, eye cancer would focus on the affected eye only. However, that is not the reality. The cancer cells in the eye could spread out to brain and bone marrows. Under this circumstance, the condition is known as advanced stage of cancer.

Based on the above discussion, what is the suggested reaction of the parents in response to the doctor’s verdict that our child suffered tumor? The first thing to do is remain calm, since it is not certain whether the said tumor or mass is malignant.
Follow doctor’s suggestion if further examination is required. The purpose is to determine whether the said tumor or mass is non malignant or malignant.

In the event that the mass proves to be malignant, of course we should be thankful. If proven otherwise, we should always be grateful since the said tumor is found at early stage. As we all know, cancer found at early stage is easier to be treated compared to one found at advanced stage.

One day, a mother asked, “Why my child could have cancer? I have taken special precaution to take care of him by not allowing him to eat foods with preservatives and others.” Similar questions also asked by other mothers whose children suffered cancer.

Could Childhood Cancer be Prevented?

Childhood cancer is different than adult cancer. Cancer in adults could be prevented, while childhood cancer could not.

In reference to this, mothers would usually asked, “If could not be prevented, what is the use of parents teaching healthy living style and eating behavior on children?” It is imperative that healthy living style and eating behavior still have to be taught to children at early age. It is not only to prevent cancer during childhood age, but also
to prevent growing children into adulthood from suffering cancer during mature age.

The International Union Against Cancer, or known as UICC, suggested to parents to teach their children, amongst others, not to smoke, eat with balanced nutrition and follow immunization program in their respective countries.

This is aimed to prevent the children at mature age from lung cancer, colon cancer, hepatitis, cervical cancer and other cancerous types that only affected adults.

Many parents blamed themselves if the child suffered cancer. They thought that they are the cause of all problems happening to the child.

It is expected that after reading the above explanation, parents could be aware that such understanding is incorrect. Hopefully the said explanation could clarify parental knowledge on childhood cancer.
Early Detection of Childhood Cancer
Could it be done?

In a public workshop, a woman asked, "in adult life, we know there is check your own breasts (SADARI) for early detection of breast cancer and Pap smear for cervical cancer. Is there any similar method for early detection for childhood cancer?"

Good Question!

Frankly and has to be admitted that to date, of all types of childhood cancers, only one can be detected at early stage, which is eye cancer or retinoblastoma. Early detection is an effort to discover cancer at early stage. As we all know, should cancer be determined at early stage, then the possibility for recovery could be bigger than compared if found at advanced stage.

As a result, in relation to childhood cancer, it is important for parents to know and be aware of the symptoms of childhood cancer; bearing in mind that only one type of childhood cancer could be detected at early stage.

Early detection for retinoblastoma is called “red light”. The examination could be done by a trained health worker, not necessarily has to be by a doctor working in a large hospital. In community health centers, the examination could be done by using a tool called ophtalmoscope, a device to see the inner eyeball of the child under examination.

Retinoblastoma happened to infants. During the examination, usually the child will be asked to sit on his mother’s lap. Meanwhile, the examinator would sit right in front of them.

Should the child’s eye under normal condition, then the examinator, through ophtalmoscope, will see red dot reflected in the child’s eye. On the contrary, the examinator would suggest for the parents to bring their child to a more comprehensive medical facility, in the absence of red light reflected from the child’s eye. It is also possible for the examinator to see red light if the child’s eye is
squeinted. Therefore, it is important for the examiner to know whether the child under inspection already has squinted eye or not.

Nowadays, with the red light procedure, it is expected that parents will check their child every once a year during infant stage. No one would want to have his child suffered retinoblastoma. However, if God is willing, then at least we would have been able to detect at early stage.

Then what about the other types of childhood cancer? Hopefully in the short run, the experts would found appropriate solutions in early detecting of other types of childhood cancer.

In the meantime, please do not stand still. Please stay alert to symptoms of childhood cancer.

Generally speaking, childhood cancer can be categorized into two major groups. For ease to be remembered, cancer can be liquid or solid. The liquid part in human body is blood. So the first group is referred to as blood cancer or also known as Leukemia.

Meanwhile, the solid form could be seen as mass found in all human body parts, such as brain, eyes, liver, kidney, amongst others. Blood cancer or Leukemia, as has been elaborated earlier, could happen to anyone. Leukemia is most common cancer type found in children.

The usual “crime scene” of Leukemia is in bone marrow. So then we asked,
“Where is bone marrow located?”

Imagine we are eating chicken drumstick. Once the meat is gone, the bone is broken, and the mid part of it usually can be sipped. That part is called bone marrow.

Bone marrow produces red blood cell (erithrocyte), white blood cell (leukocyte) and platelets (thrombocyte).

Picture bone marrow as a manufacturing facility. Problems arised when the workers in the leukocyte factory started to strike. They prevented the factory to operate. Not satisfied with having strike in their own factory, they went to erithrocyte and thrombocyte plants. Likewise, they also prevented the two plants to operate. As a result, the level of erithrocyte and thrombocyte in the blood also lowered.
Still not satisfied, the said workers continued to expand outside to other territories, including to brain, gum, skin, bone, liver, kidney, lymph, and testis.

What could be seen in a child due to the above?

In the event that erithrocyte level dropped, the child would look pale. In addition, the child would often having fever without certain causes due to leukocyte level in the blood is also low and bleeding, such as skin bleed, gum bleed, or nosebleed, due to lower thrombocyte level in the blood. If the above two or three symptoms found in a child, it may be that the said child suffered from Leukemia.

In addition to the above symptoms, other symptoms could also be found as a result of cancer cell expansion to other parts of the body, such as convulsions, gum swelling, bone pain, bigger stomach and swollen and hardened testis.

In the event that the parents noticed such symptoms, they should take their child immediately to the doctor to confirm whether such symptoms are really the signs that the child has been attacked with Leukemia. If not, of course, we should be grateful. However, if indeed the said symptoms are leading to Leukemia, we still have to appreciate, as that mean the Leukemia found in the child is still at early stage.

The earlier and faster the child having cancer be treated, the larger probability that the child to be cured. So it is imperative that parents are aware of cancer symptoms since early stage, especially Leukemia.
Now that we understand the big picture about liquid cancer type known as Leukemia, it is time to learn about solid tumor on children.

Solid tumor is usually found in almost all human body parts of a child, from head to toe. Parents usually can feel tumor or mass on a child’s body during bath. In line with the agreed principle, immediately bring the child to community health centers, hospital or other health facility. The aim is to confirm whether the mass felt in the body of a child is cancerous or not.

The following needs for the parents to be alert when seeing or felt the mass on the eye, neck, lung, stomach, genitals, hand or foot and brain.

A. EYE

Parents should be suspicious if the eye of a child looks like cat eyes, red, having sight problem or squint. Especially for red eye, usually parents would give eye drops that are easily found in the market. Parents are allowed to do so, however, if after three days there is no improvement, the child must be immediately taken to community health centers, hospital or other health facility. It could be not just a mere eye problem, but initial symptom of retinoblastoma.

B. NECK

Beware if found mass in a child’s neck that grown within a short period of time. Usually the child would not complain of pain if the said mass be pressed or felt or burning when touched. It is quite different than a mass caused by infection, which would be painful when pressed or touched or burning when touched.

Tooth and ear infections could also have similar masses as above. It is imperative to confirm the symptoms given different treatments in both cases required.
C. LUNG

If a child is out of breath and after taking scan of the chest, cancer cell found in the lungs, then do not think that the child has lung cancer. There is no lung cancer on children. This is usually due to invasion of other certain types of cancer into the lungs. One of the childhood cancer type that spread out to the lungs is bone cancer.

D. STOMACH

Many organs found in the stomach, including liver, kidney, ovary and others. All the above organs could be affected with cancer. Physically, the child’s stomach would looked swollen, and a mass would be felt if pressed. Please take the child immediately to the community health centers, hospital or other health facility centers. Other things that the parents needed to pay attention to is not to pressed the child’s stomach too often, which would keep enlarging, as that would resulting in expansion to other areas.

E. GENITALS

This refers to male genitals. Physically, the size of right and left testis would not be the same, with the affected testis usually harder despite of absence of infectious signs. Cancer on testis, as in lung cancer, could be due to expansion from other type of cancer to testis, such as Leukemia.

F. HAND OR FOOT

Beware should you notice a swollen hand or foot. This may be followed by fever or pain.

G. BRAIN

The mass in the brain could not either be seen or felt. Nonetheless, parents still has to beware of the symptoms of brain cancer by watching out for causes due to mass in the brain. The symptoms, amongst others, are headache, vomiting hose, and paralyzed and balancing issue.

As discussed earlier, in general cancer could be treated and cured if found at early stage.

That is the reason as to why the parents have to understand and stay alert to symptoms of childhood cancer. Should the parents suspected that their child
suffered cancer, please bring immediately to Community Health Centers, hospitals, and other health facilities, in order to ascertain and obtain further treatment.

For example: a child that has retinoblastoma taken by his parents to the hospital at early stage and obtained a good and proper treatment, has proven to have probability level of living free of cancer for the next two years by 80%. On the contrary, if found at advanced stage, the probability level of living free of cancer for the next two years dropped by 25%.

A wise word, in relation to cancer, by Niccolo Machiavelli, said, “The faster chronic disease found, the easier it is to be cured. The later chronic disease discover, the tougher it is to be treated.”

In the event that the parents suspected that their child has cancer, it is better to bring their child to the hospital to ascertain whether the symptoms found is cancerous or not.

What would the doctor do to confirm the symptoms of childhood cancer?

The initial step that doctor take would depend on the symptoms. In the event that a child suspected of having Leukemia, a bone marrow test on the spine would be done to examine directly the source of red, white blood cells and thrombocyte.
Under Leukemia case, the microscope would reflect that white cell blood invaded bone marrow. Meanwhile, the purpose of taking bone marrow from the spine is to see whether the bad white cell blood has invaded until brain. This is imperative for doctor to know this since the treatments of pre and post invasion to the brain are different.

There is no need for the parents to be concerned on the tests. The child would be put to sleep to avoid any traumatic experience. The process is not far different than taking blood from the hand process, as usually done in the laboratorium. The differences are only on the needle size and the location of where it would be taken.

The size of the needle for bone marrow test would be bigger than the usual needle for blood collection from hand, since the said needle needed to penetrate bone. Meanwhile, the location of where bone marrow be collected would be near coccyx, pelvis, or bone below knees (for infant below 2 years).

The fluid collection from spine would also use specific needle and the location is between two vertebrae. Afterwards, the said fluid taken from bone marrow and spine would be processed and examined under microscope by special clinic pathologist.

For the child suspected with solid tumor, the confirmation is done through biopsy.

The process could be done through surgery or by using a thin needle. There is no need for the parents to be concerned about biopsy on their child.

The surgery would be done where the mass existed. The surgeon would take a few or part of the mass. If possible, the whole mass would be taken to further process and examined under microscope by specialist anatomy pathologist.

The parents needed to understand the above information with aim that the parents obtained the holistic view of what to be done to their child during diagnosis phase. All this time, there are many parents still delaying the verification process due to lack of information or concerns that there would be something happened to their child during the process.

What is the impact?

Delaying would only worsened the situation. When parents are ready, it is possible that the prevailing cancer condition changed from early to advanced stage. The probability of cure would definitely lessened compared to when cancer found at early stage. Therefore, please do not delay.
In the medical world, until to date, there are only three types of cancer treatments, namely chemotherapy, radiotherapy and surgery. We will discuss about chemotherapy, one of the cancer treatment using chemical substance to hamper cell growth. This treatment has actually been found many years ago.

There are five major groups of anti cancer medicine, namely vinca alkaloid, antimetabolite, antibiotics, enzyme and others.

These medicines could be taken orally or direct injected to blood vessel, under the skin, in between two spines, or directly to the organs that are affected by cancer.

In reality, anti cancer medicine did not always destroy cancer, as it could not differentiate between good and bad cells. As a results, all cells, both normal or not, would be damaged.

As a doctor, personally, I would say that anti cancer medicine as "stupid" medicine.

The adverse impact of this anti cancer medicine is often referred to as disturbing side effect. The side effects are mainly nausea, diarrhea, sprue, loss of appetite, loss of hair, reddish skin/bruise/dried skin/itchy, sensitive to sun, constipated, infection, fever or cold.

Therefore, it is common that a friend or family that will undergone chemotherapy would have blood test, for example every biweekly. In addition to that, other organs will need to be examined, for example liver, kidney or heart, amongst others. The main purpose of this all is to verify the impact of the medicines that are supposedly destroy cancer cells, on the normal cells.

Usually, in the event that the adverse impact on normal cells are significant, the doctor will reduce the dosage or postpone the next chemotherapy session until the normal cells recovered.

The advanced pharmacy sector to date has also facilitate reducing several disturbing side effects. For example: nausea could be addressed by giving updated anti nausea medicine based on proper protocols. To date, almost 100% of children
under chemotherapy treatment suffered no nausea. This would eventually assist to lessen their burden during treatment.

Last but not least, this information is given in order to promote understanding, not to unnecessarily alert. For those currently and to undergone chemotherapy, the above may assist to anticipate the probability of side effects. Please consult with the doctor in order to gain more knowledge on how to alleviate the side effects.

What is the Meaning of Below Terms?

CANCER
a disease due to uncontrollable body cell growth

CHILD ONCOLOGYST
comprised of checking and counting of erythrocyte, leukocyte, and thrombocyte. In the Community Health Centers, the examination could assist to detect whether a person has Leukemia or not.

LEUKEMIA or Blood Cancer
is the most common childhood cancer. Leukemia is divided into two major groups, namely lymphoblastic and mioloblastic. Both are again divided into acut and chronic. In order to diagnose Leukemia, a suspected child has to undergone a bone marrow intake. This procedure is critical given that the treatment for each type of Leukemia differs; hence, treatment could only be determined upon knowing the exact type of Leukemia.

BONE MARROW PUNCTURE (BMP)
a procedure to take blood from bon marrow in order to diagnose the existence of Leukemia or to find out if a certain type of cancer has spread out to bone marrow or not yet.
ANESTHESIS
a technique to put someone to sleep prior to take any traumatic procedure.

CT-SCAN (Computed Tomography Scan)
a radiology examination using X-ray in order to get proper picture of the body organ suspected to be affected.

MRI (Magnetic Resonance Imaging)
a radiology examination using magnet in order to obtain proper picture of the body organ suspected to be affected.

PET SCAN (Positron Emission Tomography Scan)
a radiology examination using nuclear radiology in order to obtain proper picture of the body organ suspected to be affected. Through this examination, it is expected that the location of tumor and its spread area can be identified.

PROTOCOL
a term used for treatment procedure for someone diagnosed with cancer.

CHEMOTHERAPY
a use of certain group of medicines to treat cancer. Two common other medical terms describing chemotherapy are antineoplastic and cytotoxic.

VINCristine, 6MP (Mercaptopurine), DEXAMethasone
names of several chemotherapy medicines used for some cancer treatments.

Intratecal
a procedure to inject chemotherapy medicine into brain in between two spines.

Remission
a positive response after someone finished chemotherapy in treating his cancer. As in leukemia patient, after a phase of treatment, a patient will be evaluated by re-examine his spine. If there is no longer Leukemia cells found, or still exists but still at tolerable level, the patient is declared as remission.

Central Line (Central Vein Access)
access to inject liquid, medicine or others into someone’s body through Large Vein.

Hickman Line
a form of central vein access, which once planted, could be used for more or less three months.

Observation
an act aimed to monitor the development of certain diseases.

Erythrocyte
red blood cells that carried oxygen throughout the human body

Anemia
a condition where the amount of red blood cells fall below normal level.

Leukocyte
white blood cells that play a major role in body immunity.
NEUTROPENIA
a condition where the amount of neutrophil (ligament and segment), which are paret of white blood cell, is abnormally low.

THROMBOCYTE
blood platelet that play a role in blood clotting.

APHERESIS
a procedure to remove blood component. In the event that leukocyte is taken out, the process is called Leukopheresis. In the event that thrombocyte is taken out, the process is called thrombopheresis. Other components outside of leukocyte and thrombopheresis are then injected again to the body of the donor.

STEM CELLS
cell obtained from bone marrow, cord, blood, and other organs used for transplantation.

AUTOLOGUS
transplantation process using stem cells from its own user.

ANTIBODY
a protein that plays important role in the human immune systems, as it identified and neutralized organisms, like virus, bacteria, fungus, and other organisms that are not supposed to be in the human body.

VIRUS
a micro organism that could cause infection.

List of hospitals that can serve childhood cancer patients in all regions in Indonesia

1. Rumah Sakit Kanker “Dharmais” - Jakarta  
   Jl. Let. Jend. S. Parman Kav. 84-86, Slipi - Jakarta Barat  
   Telp. (021) 5681570, 5681571, 5681575

2. Rumah Sakit Anak & Bunda Harapan Kita - Jakarta  
   Jl. Let. Jend. S. Parman Kav. 67, Slipi - Jakarta Barat  
   Telp. (021) 5668284

3. RSPAD Gatot Subroto - Jakarta  
   Jl. Dr. Abdul Rahman Saleh No. 24 - Jakarta Pusat  
   Telp. (021) 3440693

4. RS Fatmawati - Jakarta  
   Jl. RS. Fatmawati, Cilandak - Jakarta Selatan  
   Telp. (021) 7501524

5. Rumah Sakit Cipto Mangunkusumo - Jakarta  
   Jl. Diponegoro No. 71 - Jakarta Pusat  
   Telp. (021) 3918301 - 11

6. RSU Tangerang - Tangerang  
   Jl. Ahmad Yani No. 9 - Tangerang  
   Telp. (021) 5523507

7. RSUP Dr. Hasan Sadikin - Bandung  
   Jl. Pasteur No. 38 - Bandung  
   Telp. (022) 2034953, 2034957

8. RSUP Dr. Kariadi - Semarang  
   Jl. Dr. Sutomo No. 16 - Semarang  
   Call center : (024) 8450800

9. RSUP Dr. Sardjito - Yogyakarta  
   Jl. Kesehatan 1 Sekip - Yogyakarta  
   Telp. (0274) 587333, 515408

10. RSUD Dr. Soetomo - Surabaya  
    Jl. Mayjen Prof. Dr. Moestopo 6-8, Surabaya  
    Telp. (031) 5501078, 5501111
11. RSUD Moewardi - Solo
Jl. Kolonel Sutarto No. 132, Jebres, Surakarta, Jawa Tengah
Telp. (0271) 634634, 642642

12. RS Sanglah - Bali
Jl. Diponegoro - Denpasar Bali
Telp. (0361) 227911

13. RSU Wangaya - Bali
Jl. Kartini No. 100 - Denpasar Bali
Telp. (361) 222487, 222141

14. RSUP Prof. Dr. R. D. Kandou - Manado
Jl. Malakayang, Manado - Sulawesi Utara
Telp. (0431) 853191

15. RSUD dr. Zainoel Abidin - Aceh
Jl. Teungku Daud Beureuh No. 108 - Banda Aceh
Telp. (0651) 22077, 28148

16. RSU H. Adam Malik
Jl. Bunga Lau No. 17 - Medan
Telp. (061) 8360381

17. RSU Dr. M. Djamil
Jl. Perintis Kemerdekaan - Padang
Telp. (0751) 32372

18. RSU Dr. Sudarso - Pontianak
Jl. Dr. Soedarso No. 1 - Pontianak
Telp. (0561) 737701

19. RSU Dr. Wahidin Sudiohусudo - Makassar
Jl. Perintis Kemerdekaan KM 11 - Makassar
Telp. (0411) 510675

20. RSU Arifin Ahmad - Pekanbaru
Jl. Diponegoro 2 - Pekanbaru
Telp. (0761) 21648, 21657, 23418, 855702

21. RSU Dr. M. Hoesin - Palembang
Jl. Jend. Sudirman KM 3,5 - Palembang
Telp. (0711) 354088 ext. 801

22. RSUD Ulin - Banjarmasin
Jl. Jend. A. Yani 79 - Banjarmasin
Telp. 05112180

23. RSUD Sanggau
Jl. Jend. Sudirman Kompi. Beringin - Kapuas
Telp. 056421070, 056422775

24. RSUD Lubuk Linggau
Jl. Yos Sudarso, Lubuk Linggau
Telp. (0733) 321013

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**CHILDHOOD CANCER WARNING SIGNS**

1. Pallor, bruising or bleeding, general bone pain

2. Lumps or swelling - especially if painless and without fever or other signs of infection

3. Unexplained weight loss or fever, persistent cough or shortness of breath, sweating at night

4. Eye changes - white pupil, new-onset squint, visual loss, bruising or swelling around the eyes(s)

5. Abdominal swelling

6. Headaches, especially if unusually persistent or severe, vomiting (especially early morning or worsening over days)

7. Limb or bone pain, swelling without trauma or signs of infection

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*This joint campaign is prepared by UICC, SIOP, and ICCP in celebration of International Childhood Cancer Day 2014

*International Childhood Cancer Day is celebrated every 15th February
'rumah anyo' is a temporary residence for the childhood cancer patients, which is located close to Dharmais Oncology Hospital and Harapan Kita Hospital at below address:

Jl. Anggrek Nelli Murni Blok A/110, Slipi, Jakarta Barat
Phone. (021) 534 6529, 536 62853 | Fax. (021) 536 62853

The capacity is 18 patients, where each patient is to be accompanied by an adults.

To date, the cost is only Rp 5,000/day/family (patient and his accompanion)
*Already including meals

Yayasan Anyo Indonesia also willing to be invited to be guest speaker, especially for Greater Jakarta area for free, to provide education about childhood cancer. We will invite an oncologist as speaker. We could cater for corporates, religious communities, universities, schools, social gatherings, amongst others.

For further information, please contact : (021) 534 65 29

Bank Account for Yayasan Anyo Indonesia
Bank Mandiri 164 0000 582 421 or BCA 084 524 4010

Visit our website : www.yai-indonesia.org
Email us : yai@yai-indonesia.org

a member of

we care for cancer kids with a smile