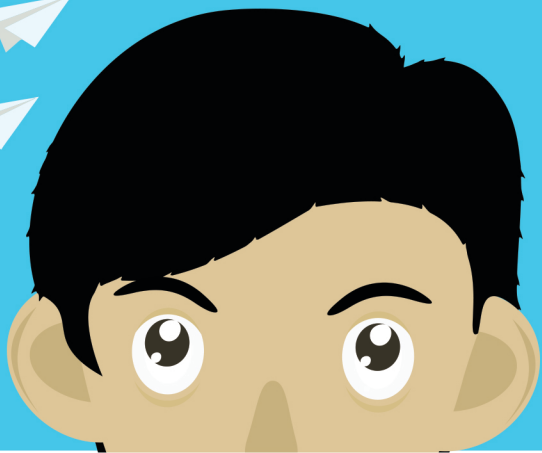




DIPONEGORO
UNIVERSITY
SEMARANG

A book for young women with
**CONGENITAL ADRENAL
HYPERPLASIA**



A book for Young Women
with

Congenital Adrenal Hyperplasia

Authors

Agustini Utari

Ayu Kurnia

Ibtichal Gusyani Putri

Annastasia Ediati

Diponegoro University

2017

Copyright is protected by law

This book may be reproduced and quoted for the purpose of patient education with appropriate attribution and may not be used for profit.

First published in 2017

Contributors

Agustini Utari (Faculty of Medicine, Diponegoro University, Indonesia)

Ayu Kurnia (Faculty of Psychology, Diponegoro University, Indonesia)

Ibtichal Gusyani Putri (Faculty of Psychology, Diponegoro University, Indonesia)

Annastasia Ediaty (Faculty of Psychology, Diponegoro University, Indonesia)

Graphic design layout

Najah Anindya Aisya

Irene Astrid Larasati

Comic Illustrations

Abigail Natalini

Image Sources

freepik.com

pinterest.com

Author Contact

agustiniutari@gmail.com

ediati.psi@gmail.com

Publisher: Undip Press
ISBN 978-979-097-430-2

FOREWORD

Becoming a young adult and moving into secondary school is an exciting time with new friends and more personal freedom. However, young adults also experience more sensitive feelings as they start finding their identity, becoming more independent, and being responsible for making decisions. Moreover, challenges that interfere with these processes during this time can be particularly difficult to deal with. One of these difficulties is puberty. Physical changes for young women include growing breasts, armpit and pubic hair growth, changes to body shape, and the start of menstruation.

Congenital Adrenal Hyperplasia or CAH is a genetic condition leading to enlarged kidney glands and inability to produce the hormone cortisol (a hormone which helps to regulate the immune system, energy, and helps to cope with stress), in some cases inability to produce aldosterone (which helps in salt regulation), and too much androgen production (male sex hormone). For young women with CAH, too much androgen often causes various psychological challenges.

Whilst the families of girls living with CAH in high income countries can usually affordably access the medicines and treatment needed to achieve a very high quality of life, it can be very difficult for families in resource poor countries to afford or access the medicine and healthcare needed to manage their daughter's CAH. Not taking medicines regularly can cause many challenges for young women living with CAH, including: abnormal breast growth, lack of menstruation, deep voice, large Adam's apple, facial hair growth, and dark and rough skin. This can be prevented and overcome with early detection and diagnosis and regular medication. However, for those who experienced late detection of CAH or do not take the correct medications, the above-mentioned challenges can occur, and may also cause psychological health issues.

Psychological issues can include feeling different from others, having low self-esteem, having unstable emotions, being offended easily when people talk negatively about having CAH, worrying about the future, concern about making friends and building relations with the opposite sex (dating), stress resulting from being teased, and difficulty learning how to be open with others.

This book hopes to help with challenges which can affect young people with CAH, particularly young women. To be a source of inspiration for those who are feeling the difficulties of their condition instilling in them a spirit of optimism and determination. This book is packed with interesting discussions so it is easy and fun for young women to read. Each section begins with a real story from a young person living with CAH in Indonesia, which we hope will be a light and motivation for young people with CAH, wherever they are in the world.

Warmest greetings,

All contributors





The stories in this book are based on true life stories from young people with CAH. The names used are pseudonyms. Similarities in the stories' plot and setting are not intentional



This is a letter that a young woman sent to us about the challenges of living with CAH and how to overcome them

dear diary,
my morning look in the mirror shows the usual: dark and dull skin, a few pimples appearing, the moustache and beard that i shave daily. i'm actually a girl, but there's something a bit different with my body. my voice is deeper like a boy's, my shoulders are wide and i'm stronger than most girls my age. am i still a girl? i get embarrassed when i think about it and people often tease me about the appearance of my body. would it be better if i just stay by myself and don't try to make friends?

people can't tell if i'm a boy or a girl. it's really hard to hide my condition. but what else can i do. the mirror doesn't show that i'm a normal girl. it's not just me who feels uncertain, even my parents are worried about me, although they say that i'm a girl.

Semarang, 17 December 2013

Cahaya

GUIDE

OUR LIVES,
YOUTH WITH CAH

#3
Am I a boy or a girl? (pg. 6-7)

#4
Why am I short? (pg. 8-9)

#1
I already get my period, do you? (pg. 1-3)

#2
Why is my voice so deep? (pg. 4-5)

#5
Why do I get angry easily? (pg. 10-11)

#6
I want more friends (pg. 12)



#9

Can I have a family in the future?
(pg. 16)



#8

How can I be better at taking my medicines?
(pg. 14-15)

#7

Can I dream?
(pg. 13)

#11

Do I deserve love?
(pg. 19)

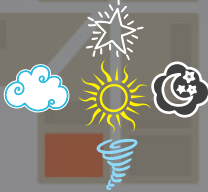
#10

How can I be more self-confident and open?
(pg. 17-18)

#12

How can I deal with teasing?
(pg. 20)

PIECE OF THE STORY



MEET THE DOCTOR (pg. 22-23)

1. *Can people with CAH be cured?*
2. *Do I have to take medicine for the rest of my life?*
3. *What would happen if I didn't take my medicines regularly?*
4. *What are the side-effects of taking the medicines for my whole life?*
5. *Can I menstruate normally like my friends?*

OUR LIFE, YOUTH WITH CAH





What's up?
Have you got your
period?
Me too. I'm feeling a
bit cranky.

Owww, my
tummy hurts..

I know right...

Why don't I get
my period?



#1

I get my
period,
do you?



Starting menstruation, or 'getting your period' can be something that *young women* look forward to. It may also cause young women to feel scared, anxious and of course curious.




Turns out there are many stories about the first time someone had their period


Some are **happy**, some are **confused** about the best way to use pads and tampons, some are **scared** to see the blood, some are in a lot of **pain**, some end up **crying** or even fainting, and many other stories.



But there can also be other challenges when all our friends already have their period but we don't. We can feel really different and uncomfortable when our friends are talking about it.



Hello I'm Bintang, I'm a CAH patient. I'm waiting for the doctor to help me with my medicines. And you?



Oh... I'm Bulan, I'm a CAH patient too but I haven't been taking medicine. I'm feeling sad because I haven't had my period yet.

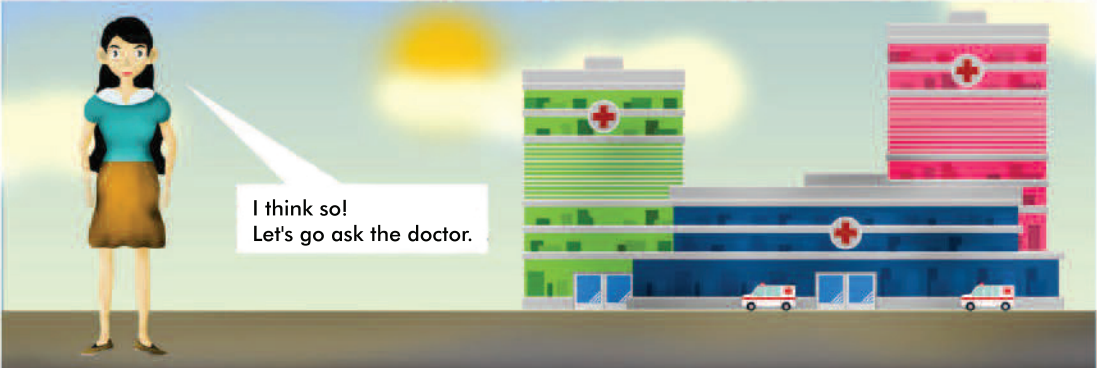


Oh you don't take medicine?

Yeah, it's been a very long time I haven't received treatment.

I started getting my period in junior high school . The doctor said it's because I've been taking medicine regularly since I was a baby.

Oh. So you mean if I take medicine regularly I can be like you?



I think so!
Let's go ask the doctor.



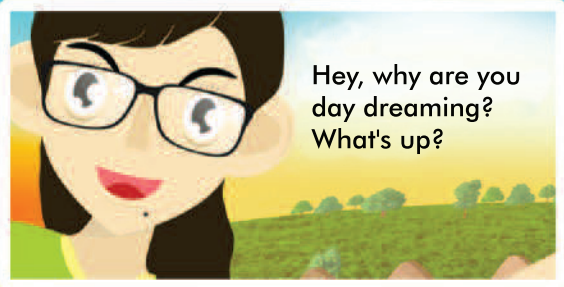
**AM I
NORMAL?**

**CAN I
MENSTRUATE?**

*These questions often come to our minds.
It does sometimes happen that young women with
CAH don't get their periods at all.*

*All young women with CAH are capable of
menstruating normally, because their internal
reproductive organs are the same as other women.*

- ▶ **Menstruation** is a process that occurs in the body because of female hormones such as **estrogen and progesterone**.
- ▶ **For young women with CAH who don't take medicine**, the level of male hormones will be very high. The male hormones, mainly androgen, can upset the balance with the female hormones. The result for young women with CAH who don't take medicine regularly is that it will be very hard for them to have a regular menstruation pattern.



Hey, why are you
day dreaming?
What's up?



Why haven't I
started
menstruation?



Be calm and take a deep breath. Then, turn your head twice to the right and twice to the left. Now, try laying down on your back with your legs bent and palms on the ground next to your ears. Slowly lift your waist and push through your feet and hands to create a Bridge Pose.

So, What's the Solution?

1

Visit a paediatric endocrinologist or pediatrician soon for a check-up.

2

Take your medicines regularly, so that they make your body's hormones more in balance.

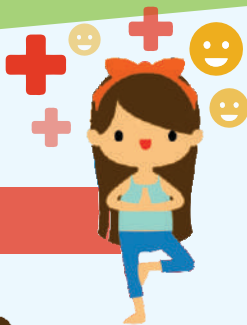
3

If after taking the medicines you still don't menstruate, be patient and keep taking the medicines for a little longer, because your hormones need time to adjust.

AND DON'T FORGET

1

Stay positive



2


KEEP BELIEVING IN YOURSELF



3

Tell someone you trust about your challenges and concerns






Please sing one by one so you can be judged for the audition.



Lalalalala.....
lalalala



Oh no, my voice sounds like a boy's... They'll probably make me sing in the boy's section...



#2 Why is my voice SO DEEP?

Deepening of the voice is one of the signs of puberty for boys, but it can be difficult if it happens to girls. This is because for most girls, their voice doesn't change much during puberty.

For young women with CAH who don't take medicine regularly, their voice may deepen during puberty, which can be challenging .

This can happen because of exposure to high levels of male hormones, due to medicines not being taken regularly, which results in growth of the Adam's apple and of the voice.

A deep voice can sometimes be considered weird by other people and they might even use it as a taunt. If this happens, women with deep voices can lose self-confidence and withdraw from social interactions.

HOW TO NOT FEEL SHY AND OVERCOME CHALLENGES WITH HAVING A DEEP VOICE?

Don't worry; having a deep voice is not everything.

We can still make use of all our talents and have achievements and a happy life. We are capable of success as young women with CAH. Just look at the stories in this book; **young women with CAH remain capable of leading good and successful lives when they have regular medication.**

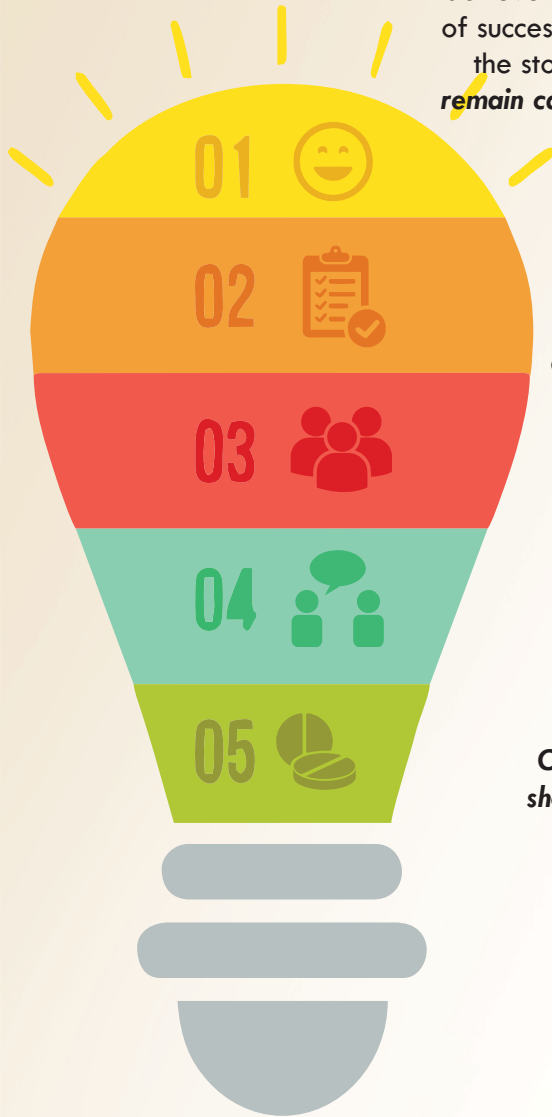
Focus on the things which lead you to positive activities.


Sometimes we need to just care less about what others think. **Find your talent and then find a way to make the most of it.**

Put yourself in a good environment with good friends, who can motivate you and accept you as you are. This will help you feel confident.

Share your concerns and challenges with someone you trust, so that your load is lightened.

One more thing which is very important and should not be forgotten: **take your medicines regularly following your doctor's recommendation.** Taking your medicines regularly will help with these challenges.





My skin is rough and dark,
I have lots of body hair,
and my breasts are not
growing like other girls.
Am I a boy or a girl?

#3 Am I a boy or a girl?

When you are a teenager, there are so many important questions in life. There is a lot to think about.



Young adults usually think a lot about how they, and others, look. Skin conditions like acne and oily skin can affect the self-confidence of young women.

The physical signs which may appear in young women who don't take regular medication include:

- ◀ Rough and dark skin
- ◀ Small breasts
- ◀ Coarse and dark hair on the face, armpits, and pubic region

SOLUTION

CONFIDENCE

Know that everyone will face different challenges in life, so accept your challenges with the confidence that you are capable of overcoming them. Believe in yourself; that you have the potential to thrive.



TAKE MEDICINE REGULARLY FOLLOWING YOUR DOCTOR'S INSTRUCTIONS

With proper medication, dark skin will lighten and breasts will develop.



SEE A PSYCHOLOGIST

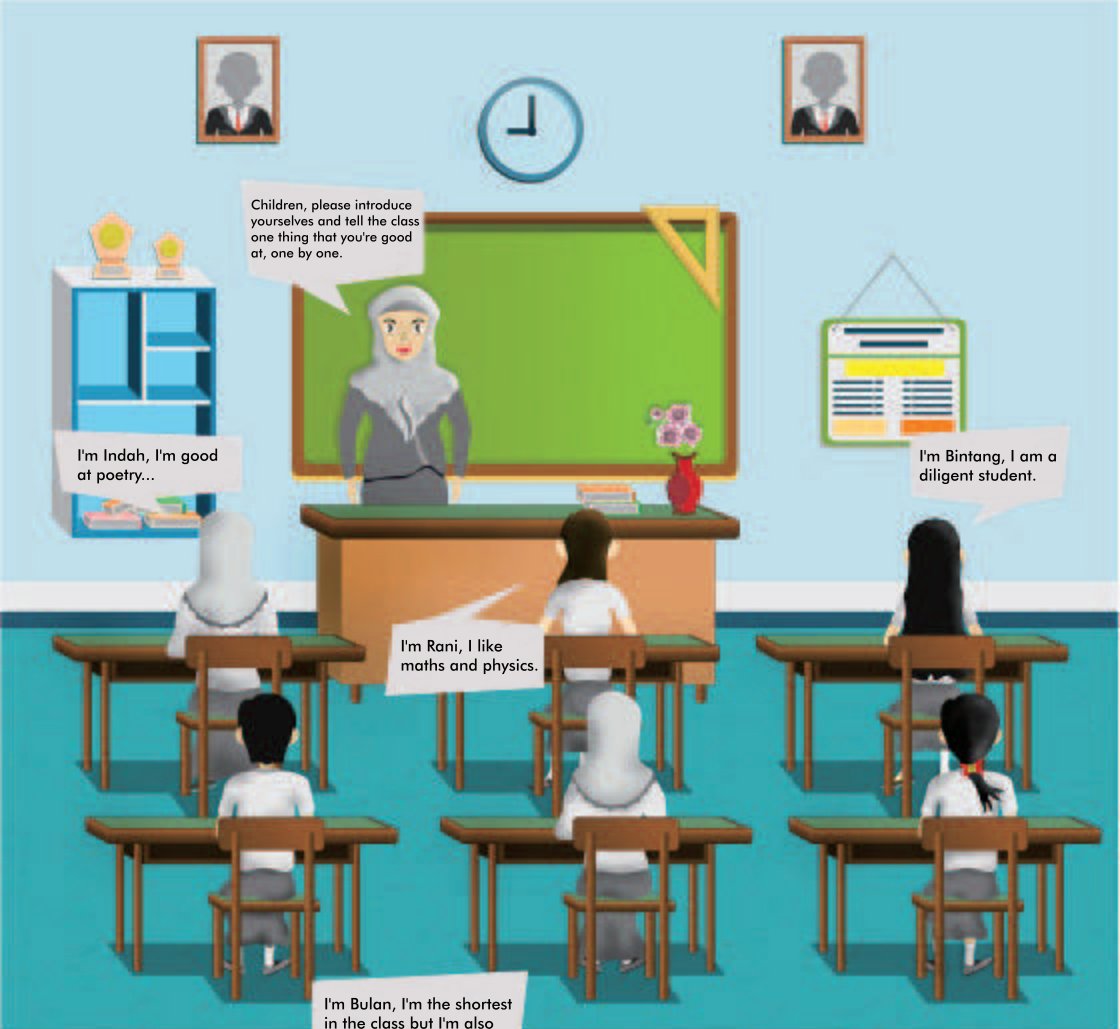
Seeing a psychologist can help you find your sense of self and better understand your desires, which will alleviate burdens and allow you to prepare for the future.

OVERCOME PHYSICAL CHALLENGES

TAKE CARE OF YOURSELF

Keep taking care of yourself with a clean and healthy life, because with an organised life we can start the day cheerfully. Also, we can make a routine of removing hair from areas where it is not wanted.





An illustration of a giraffe and a person standing on a green patch of ground against a blue background with white clouds and green leaves. The giraffe is on the left, and the person is on the right. The giraffe's neck has a ruler-like scale. The person is significantly shorter than the giraffe's neck. The giraffe has a red bow on its head and a colorful saddle on its back. The person has dark curly hair and is wearing a white t-shirt and blue pants.

#4

Why am I so short?

Body height is often important to teenagers. Young people with CAH who don't take their medicine regularly or were diagnosed late can have a childhood growth period which is faster than usual.

*Early on, children with CAH will be taller than their friends. This is because of higher levels of testosterone in children with CAH which will be partially converted to estrogen and will cause bone maturity to occur faster. **When bones mature, they lose their ability to keep growing, meaning that growth will stop sooner.** This is why the final height of young people with CAH can be shorter than their friends.*

WHAT IS THE SOLUTION?



#1

**Take
Medicines
Regularly**



#2

**Learn to
be
Grateful**



#3

**Think
positive**

Take medications according to the dose and schedule given by the doctor.

Most of us will never feel satisfied with ourselves. So, if the doctor says our bones have matured and we will not grow any taller, we must learn to love and accept ourselves the way we are.

Don't be disappointed, for many jobs it doesn't matter if you are short or tall. We must choose what suits our best, remain positive and focused on our strengths, and achieve our dreams.



I am a girl,
but my voice is deep,
my body is stocky, and I have
coarse body hair, not like my little sister
who is beautiful and has a soft voice.

My friend said
my skin is really black
like charcoal.

Many people tease me
and call me a boy.

***How should I
respond to
all this?***



#5 Why do I get angry so easily?



Do you sometimes get easily offended by what your friends or others around you say?

This feeling sometimes arises when young people have unstable emotions in the days before menstruation. Besides that, these uncomfortable feelings can arise when there's a lot on your mind, which leads us to outwardly express emotions like annoyance and anger toward others.

“Being angry is normal and OK if it happens occasionally, but it can be a big disturbance to our lives if we feel angry often.”

For young people with CAH they might feel overwhelmed with different things that happen in their lives, For example feeling annoyed at having to always take medicine or always being asked questions about themselves. Feeling angry is a negative emotion which is not good for us. Being angry can make it more difficult to solve our challenges, and can even cause various physical illnesses that interfere with activities

WAYS TO CONTROL ANGER

1 SMILE WHEN MET WITH A CHALLENGE

Smiling will help you to feel happier. Try to remind yourself that anger is not a good way to solve challenges.



3 WHEN THERE IS A CHALLENGE, BE CALM, OPTIMISTIC, AND BRAVE



2 DO THINGS THAT MAKES YOU FEEL GOOD

Do things that make you feel good. You could go out with friends or try a hobby such as writing, singing, photography, or sports.

4 SHARE YOUR CHALLENGES WITH SOMEONE YOU TRUST

You can tell your challenges to someone who you are close to. This is important to help you feel calm and motivated. You might also want to talk with a psychologist about how to be better at dealing with your emotions.



HIGH SCHOOL



#6 I want to have more friends

Being different from our friends can make us feel embarrassed and shy.

Different people with CAH will react in different ways. Some don't care and will continue their everyday lives, however some will pull away from their friends. If this isolation happens for too long, we can feel lonely and be less happy about our lives.

**“THE FEELING OF NOT HAVING FRIENDS MIGHT
ACTUALLY JUST BE IN YOUR MIND”**



You might have heard people say that what we do is an embodiment of what we think. When we are open to others, they will feel more comfortable being open to us. *With a pleasant personality, a tendency to help others, warmth, and attentiveness, we can then connect with others and make sincere friendships through strong and courageous intent.*

Believe that everyone has weaknesses and challenges; no one is perfect. When we are able to support others in their shortcomings, then we will find that others support us in ours.

I want to be a doctor
or maybe a nurse or a teacher.
But can I have dreams like that?
I have a lot of challenges...



#7

Can I dream?

Everyone has the right to dream and a chance to fulfil their dreams, the difference is in the will and determination to realise the dream.

“ There are many stories of children with CAH who were able to achieve their dreams by utilising their talents. ”

So what are you waiting for?

Let's start now,

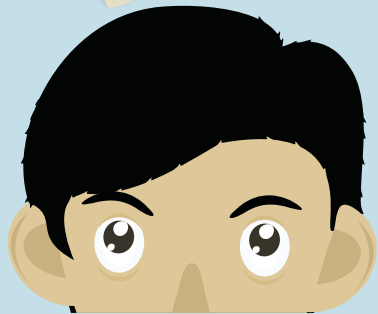
Think of your dream, write it down, and make it happen!

*Dreams are the key
To conquer the world
Run without tiring
Until you've reached your goal.
Run and laugh
Though the world is not as
beautiful as heaven
Be grateful for the power of
Our love in this world...*

*Forever...
Love life
Be always smiling
Though life often isn't fair
Love completes us*

*(Translated English lyrics to
Laskar Pelangi by Nidji)*

CAN I
dream?



The medicine is
the DEVIL
playing games
with me

The
medicines
are POISON

I hear
rumours
about the
medicines

My medicines
have many
side effects



The
medicine
tastes
BITTER

#8

How can I be better at taking my medicines?

If the medicine was once or twice every week then it would be easy, but young people with CAH must take their medicines every day, some even 3 times per day. That definitely sounds hard.

Making this situation even harder are rumours that are sometimes said about the medicines. These myths and rumours can make people not want to take their medicines properly - even though research over many years has now proven these medicines are very safe and effective for CAH.

Taking daily medicine can be a challenge in itself for young people with CAH. The main reasons for not taking medicines regularly are feeling bored or annoyed and forgetting the consequences of not taking them.



How to be better at taking medicines regularly, considering that they are so important.

1 *Strong intent*

Remind yourself that your medicines are like vitamins but for CAH patients. Your body needs the hormones in the medicines, but you cannot make them by yourself, so medicines for people with CAH are essential and safe to be taken for their whole lives.

2 *Ask a close friend or family member to remind you to take your medicines on time*

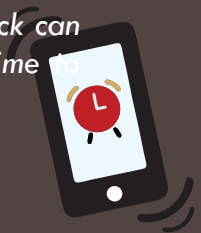
3 *Keep a record when you take your medicines*

This can help to get used to taking your medicines and see how disciplined you've been.



4 *Use your phone alarm*

Your phone's alarm clock can remind you when it's time to take your medicines.




Don't forget to take your medicines regularly.



Prepare to lead a better life by taking your medicines regularly



An illustration of a mother and daughter standing in a garden. The mother, on the left, has white hair and is wearing a green floral top and a blue patterned skirt. The daughter, on the right, has black hair and is wearing a green top and a black skirt. They are standing in front of a wooden picket fence. The background shows a bright sun in a blue and yellow sky, green hills, and a tree with large green leaves in the top right corner. A ladybug is visible on a grass blade to the right.

Daughter, work hard in school...
be kind so you can find a good
husband. Your mother wants to
have grandchildren.

Yes mum...
(Will I be able to get married
and have children like other
girls???)

#9

Can I have a family later?

Every person has the right to dream of and hope for a family. Young people with CAH still have the chance to make a happy and harmonious family. Many CAH patients are married with children and have happy families.

The most important thing to have the chance of making a family is to take your medicines regularly so that the hormones that make you grow are balanced





#10
How can I be
SELF-CONFIDENT AND OPEN?

There is a study in which participants were asked to do some strange things, for example wearing their shirt inside out or wearing mismatched shoes. Two participants were asked to display these unusual behaviours in public to see the public's reaction.

One of the participants was very confident so the people around her were not particularly aware of the peculiarities, meaning that she was able to mingle easily with those around her. The second participant was asked to act shyly and with less self-confidence, as if overly self-aware of her unusual characteristics. This drew the attention of the people around her and it was difficult for her to mingle with others.

Self-belief and openness with our surroundings are important to building relationships and having friends who will be emotionally supportive when needed.

Then how can we do this?



How can I be more self-confident and open?

1 FIND AND REACH YOUR POTENTIAL

through school activities, courses, sports and competitions. By understanding all the potential that we have inside ourselves, we can feel more and more self-confident.

2 FIND A POSTIVE ROLE MODEL

who can help to motivate and inspire you.

3 BE BRAVE

When people ask you about something, remember that your opinion is valuable. Cherish your thoughts.



JRENG...JRENG...

I'm ready to burst
with emotion....
A failed love....

rolling
21016

DEG!

DEG!

DEG!

My chest is pounding, is this what
people call love?
Do I deserve to feel this way
about him?

DEG!

#11

Do I deserve to love?

During adolescence, feelings of attraction for the opposite sex begin to emerge. Attraction to the opposite sex is quite normal in adolescence. A pounding chest and feeling very happy when meeting with someone are things that can happen when you 'like' that person.

For someone with CAH, attraction and love can be difficult. There is no issue with someone being attracted to someone of the opposite sex. **Everyone is entitled to love and to be loved.** Sincere relationships involve accepting each other's strengths and weaknesses

Taking your medicines regularly will help your body to regulate your female hormones. So keep in high spirits and don't forget to enjoy your teenage years. *



Hit anyone who teases
you!!
Come on, just hit them!!
Say something back to
him so he knows how
angry you are!!

Be patient, stay
positive and try
to be a good
friend.



#12

How to deal with teasing?

"I've never met a strong person with an easy past."

A personal challenge can be a chance to become stronger.

Teenagers do sometimes tease each other. Teenagers with CAH will very likely be teased at some time. If the teasing is taken very seriously and is thought about a lot then it can make us feel very sad, even leading to not enjoying being a teenager.



WAYS TO DEAL WITH TEASING?

APPROACH ALL SITUATIONS CALMLY AND WITH A SMILE,

remember these taunts are unimportant/meaningless.

THINK POSITIVE

because positive thoughts will help you grow to be more happy.

BE WELL BEHAVED

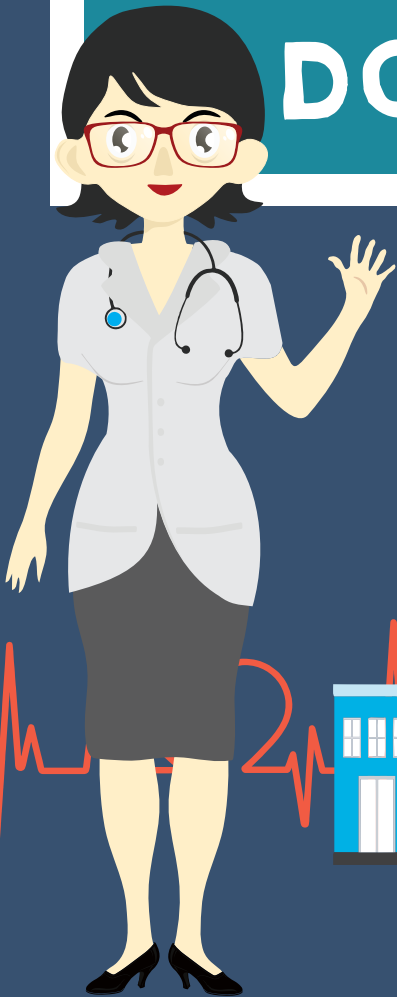
towards people who tease you.

STAY HAPPY AND POSITIVE

SHOW PEOPLE THAT YOU ARE MORE THAN WHAT THEY THINK!

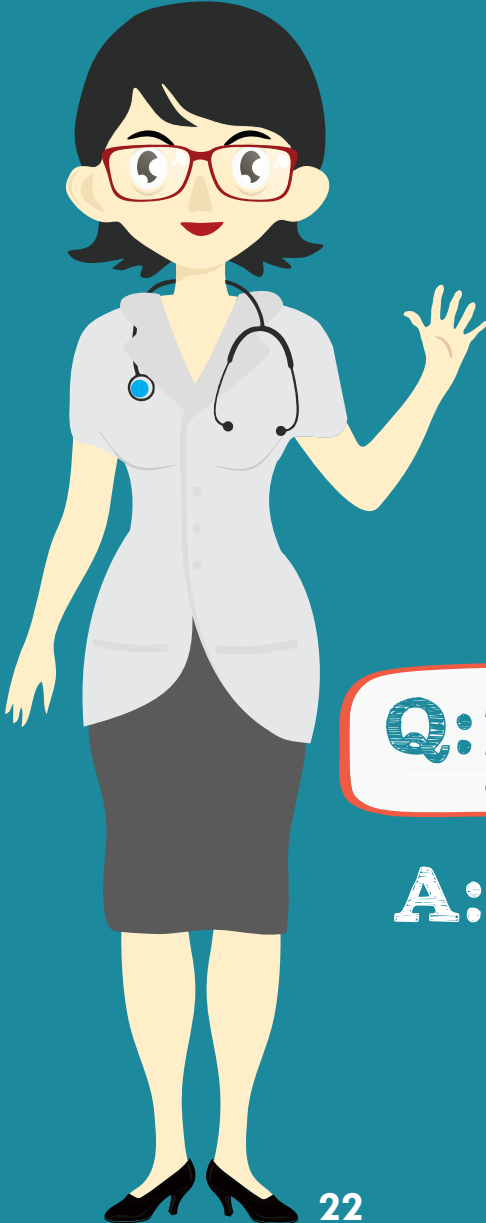


MEET THE DOCTOR



Meet the DOCTOR

Question & answer page



Q: Can someone with CAH be cured, Doctor?

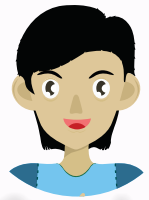
A: Someone with CAH cannot be cured, although they can be treated. Treatment replaces cortisol while decreasing the levels of male hormones (androgen and testosterone) which are too high. For the type of CAH which affects salts, treatment also adds another salt-retaining hormone. With treatment, someone with CAH can live a normal life like their friends, provided that they take their medicines according to their doctor's instructions.

Q: Do I have to take my medicine for the rest of my life?

A: Because the adrenal gland cannot make cortisol, and sometimes aldosterone, for the rest of your life, a medicine to replace this deficiency also must be taken for the rest of your life. Although the medicine must be taken for your whole life, there is no need to worry as the medicine is replacing the hormone which can't be produced by the body. Similarly to a vitamin deficient person taking vitamins, people with CAH who are cortisol deficient must take cortisol.

Meet the DOCTOR

Question & answer page



Q: What will happen if I don't take my medicines regularly?

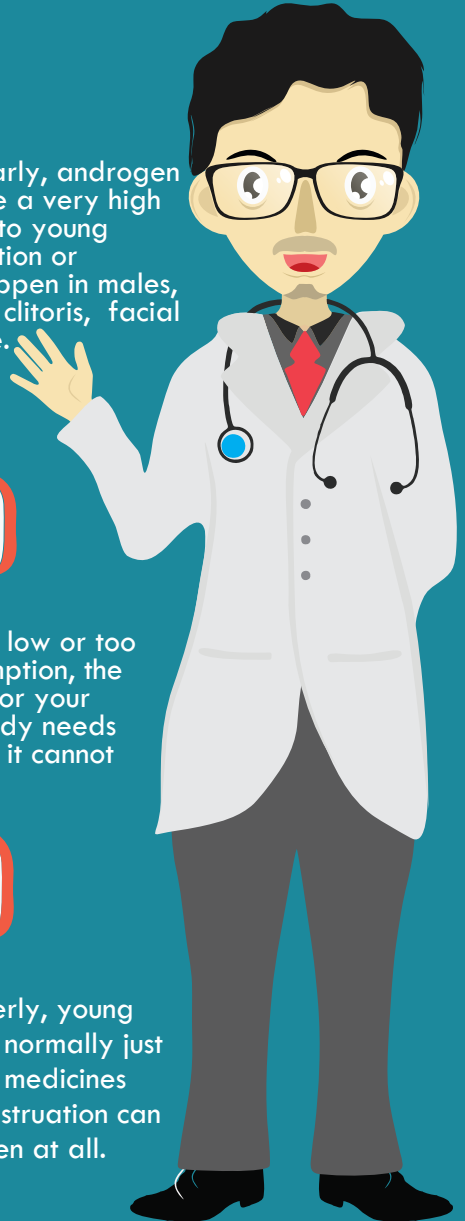
A: If medicines are not taken regularly, androgen or other male hormones will have a very high level in the blood. This can lead to young women experiencing masculinisation or physical changes that usually happen in males, for example enlargement of the clitoris, facial hair, and deepening of the voice. This can be avoided if medicine is taken regularly from a young age.

Q: What are the side-effects of taking medicines for my whole life?

A: With the correct dosage, not too low or too high, and regularly timed consumption, the medicines are safe to be taken for your whole life. This is because the body needs these medicines to produce what it cannot produce itself.

Q: Can I menstruate like my friends?

A: When medicines are taken properly, young women with CAH can menstruate normally just like their friends. However, if the medicines are not taken properly, then menstruation can be disturbed and even not happen at all.



my diary

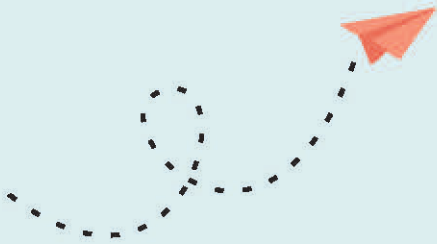
Reflecting on things every night makes me so tired. Thinking about all the things that could change the course of my life. I know that some of the things in my life will remain forever. My feelings are up and down. Tears drip down my face when I think about the days to come. Wobbling like a boat in a stormy ocean. I must soon get back on land. Or will I be stranded in this sea of emotion? For the sake of continuing, continuing to keep going until I can go no further. Exhausted, bored, hopeless, whispers tell me to stop this struggle. No, I will not stop. I must remain disciplined.

For the sake of my future self. To be acknowledged and loved as a normal woman. Now is not the time to limit my place in the world, I must live my own proof that I am worth being considered. I must be more optimistic, more spirited, so I can achieve my goals. Slowly but surely, my smile will return, when I think of all I am thankful for. My grateful smile will return when I am with others. Grateful feelings and self-belief will return to accompany my every step. I must fight to get back to the life which I should have. There is no regret, no disappointment. My struggle will pay off. I feel centered and ready to face the world. All of these struggles are lessons which I will not forget. I hope that my story will be a source of inspiration for those around me.

Semarang, 9 September 2015



**CAH INSPIRATIONAL
S T O R Y :
A JOURNEY
TO SUCCESS**







MY LOVE, MY SPIRIT

I call the sun as a friend

I grew up in a small city in Central Java. I lived in a rural area which had a temperate climate and was very beautiful. When I was still young my CAH was diagnosed and at that time few people knew about the condition. I didn't tell people about it because I thought it was too hard to explain such a foreign thing to people. After some time rumours appeared about CAH which were far from the truth. Some people said that I had brain cancer because I often went to the hospital for check-ups. I can only laugh when I hear rumours like that. Let it be that only my family and I know. At first this gossip made me feel sad and added to my worry about being told that I have to take medicine for the rest of my life. I think there were no other people in my community with CAH.

Was I the only one? When I had a check-up at the doctor I found out that there were many others with the same condition. I felt relieved but also sorry that there were other people who had the same issues as me. There is no use being sad, for me it's better to continue in a life full of optimism. I never ignore what others say. Every day I continue enjoying my life. Although at first my skin was a dark colour, my face pimply, and my body a bit fat, I believe in myself. I have many friends, not only my own age; I can make friends with all kinds of people. Joining youth activities in my village was one way to avoid being lonely.



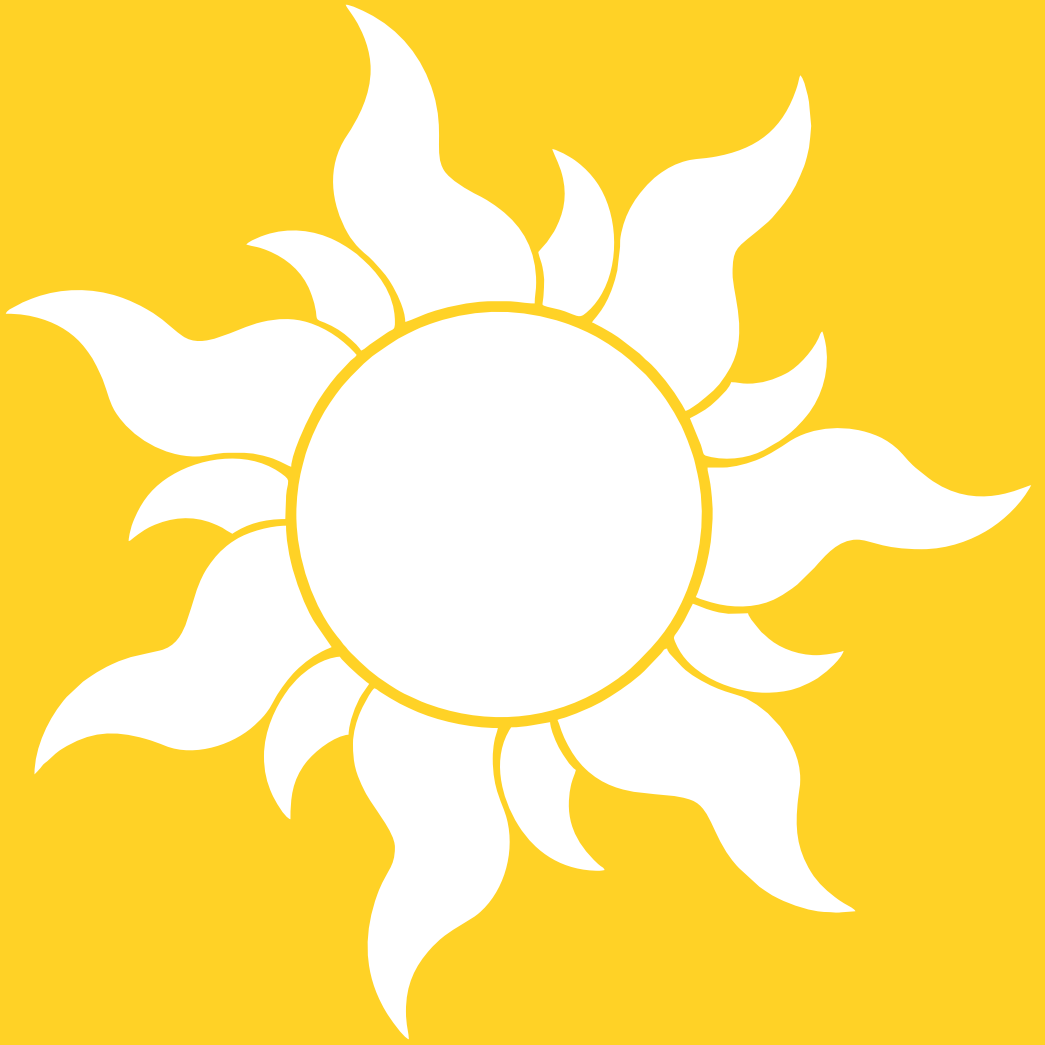
I'm still becoming used to taking my medicines regularly.

I'm becoming more confident in my abilities. I even take the time to make myself look prettier so people see me as more feminine, and I'm already good at putting on make-up. To be honest I still really want to have a normal height and better figure. Although I'm not totally satisfied with how I look, I feel happy because I feel like a normal woman and I get my period. My skin is softer and my pimples have started to disappear. And of course I'm very happy that my breasts are starting to grow.

What's added to my happiness is that there is a boy who is interested in me and wants to marry me. We are currently engaged. We have begun planning many things for our future together. My fiancé is one of my motivations to continue my therapy with discipline so my condition continues improving. He supports me by always reminding me to take my medicines. He says that if I didn't take my medicines then it would make him feel that I didn't love myself. But this is one of the ways he shows affection and respect for our future together because the impact of my health is not only on me but also on him and our future family. Our deepest desire is that later we can have a baby. **I feel lucky because I met someone who understands me and loves me as I am.**

Twilight at the end of 2016,

Matahari







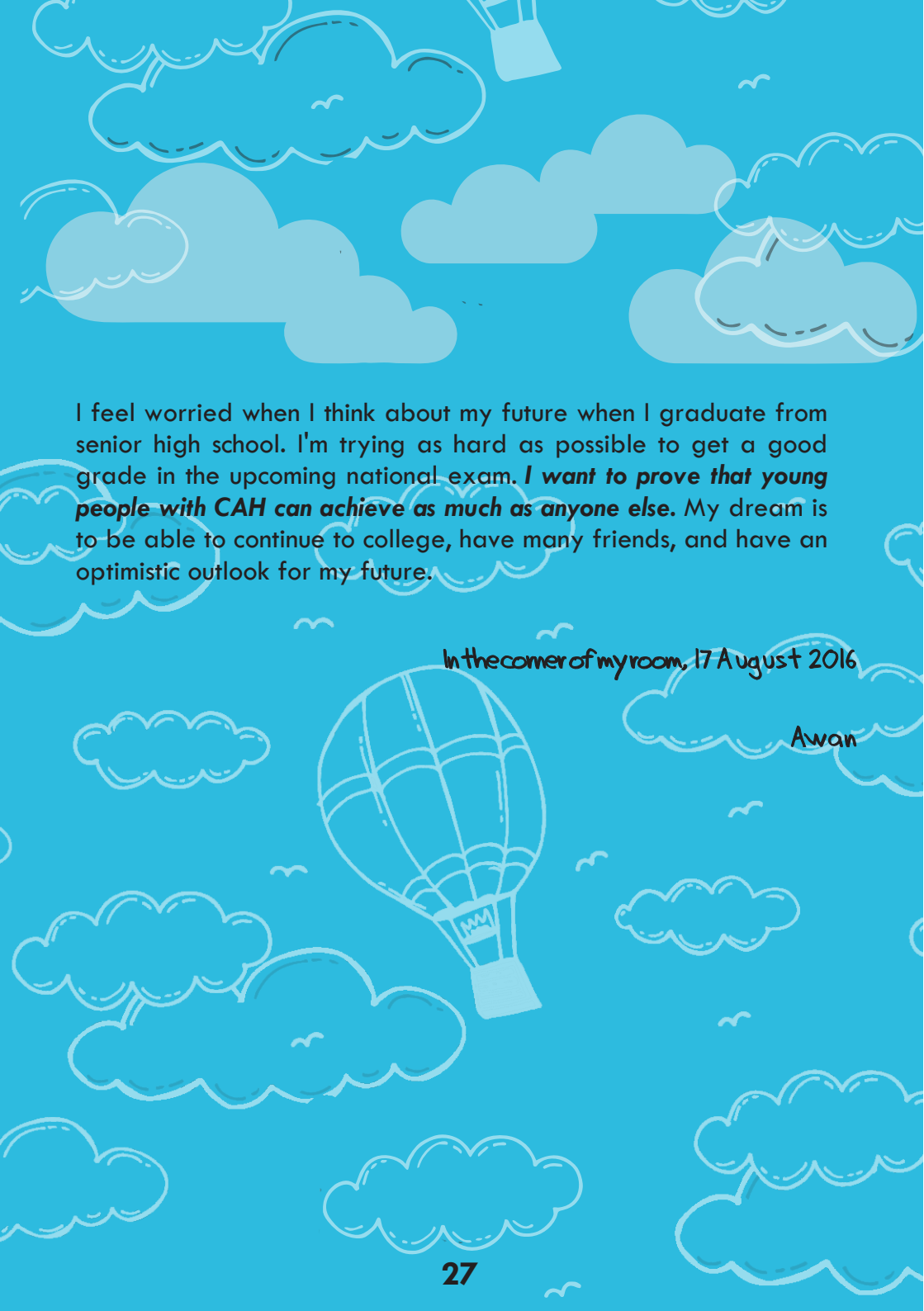
YOUNG PEOPLE WITH CAH CAN DREAM

My name is August

Right now I'm sitting in my senior high school class. Soon I will take the national exam. I have been studying hard because I really want to get into college. ***Of course I haven't been forgetting to take my medicines.*** I feel that my medicines help me to think clearly so I can study better. But not only that. Also, my appearance is changing little by little. My breasts are growing, and I have more confidence to socialise with my friends. ***I now have lots of friends,*** which is different from before when lots of people teased me about my condition.

Of course taking medicines every day means that sometimes I feel bored and lazy. And so I use forgetfulness as my excuse for not taking my medicines. Also, I have so many school activities which means that my schedule for taking medicines changes. This can lead to my period becoming irregular, my skin becoming dark, losing my focus easily, and feeling emotional. ***I feel sorry and guilty that I sometimes am not disciplined with my medicines.*** But for the last three months I have been very good with visiting the doctor for my check-ups.





I feel worried when I think about my future when I graduate from senior high school. I'm trying as hard as possible to get a good grade in the upcoming national exam. ***I want to prove that young people with CAH can achieve as much as anyone else.*** My dream is to be able to continue to college, have many friends, and have an optimistic outlook for my future.

In the corner of my room, 17 August 2016

Awan







THERE'S NO NEED TO WORRY ABOUT COLLEGE

Hello, my name is Bulan.

I was born as a girl but in my life sometimes people think my appearance and style is like a boy. When I was in primary school some of my friends started menstruating, but I didn't think about it too much because I thought that menstruation usually begins in junior high school. By the time we started senior high school, all my friends had started menstruating, except for me. Some embarrassing things started happening with my body. I started having facial hair and coarse hair in my armpits and on my legs and it was startling because it was like what was happening to boys who have a penis. I wasn't as tall as most boys but then why did my breasts not grow so that I had a flat chest like boys.

The most upsetting thing was when people mistakenly thought I was a boy. It made me feel stressed, until I would cry because I didn't know what to do. I tried to hide my body from my friends, especially when there was swimming class at school or my friends asked me to go swimming . I would turn around so that my friends could not start asking me questions. I could not answer and explain to them because I was also confused and didn't know what was happening to my body.



I didn't want my friends to stay away from me.

Until recently I would only tell and show the changes to my body to my mum. After going through a long process, the doctor said that *I have CAH and that I must take medicine for the rest of my life.* I have been given a lot of support, mainly from my family. I decided to start the medicines like the doctor said. After I took the medicines, many of the differences with my body slowly started to change.

One month after I started the medicines, at age 17, I got my first period. More changes followed, for example the hair on my face and body that was black and coarse became white and soft, then my breasts started to grow slowly, though not like other girls but I was still grateful for it.

Being frustrated, feeling lazy, and sometimes forgetting to take my medicines are obstacles to my therapy. But I must get used to always taking my medicines so that I keep getting better. I am thankful because I have learned many valuable lessons from this experience. I believed in myself that I could get into college and continue increasing my group of friends. Now I'm studying for a psychology degree in Semarang city. I want to help others who are in a similar situation to be optimistic and energised in their lives.

On a full moon, 18 November 2016

Bulan







HAVING CHILDREN AND A HAPPY FAMILY

People with CAH can't have a family?? Who said? The proof: I have a husband who loves me and am blessed with a healthy and smart daughter who doesn't suffer from my condition. The secret to this is that I take my medicines following my doctor's instructions.

At first I felt awkward about my body. I didn't develop like other girls. I was stressed and scared to think about it. At my age surely menstruation should have started but it had not. My body was dark, my voice like a boy's, and I was stockier and stronger than other girls.

I didn't want to look at myself in the mirror. How could it be, it seemed like a male body was taking over my body. Others were scared of my appearance and would not believe that I am a girl. My cousin also experienced the same changes. Eventually we decided to get a check-up and ask about our condition. After being referred to another doctor, we learned about our condition but in our area there were not yet adequate facilities so we had to go to the regional hospital. Finally, we learnt for sure that we had CAH.



*I feel lucky because
I'm not too late to
get medicines to
help me.*

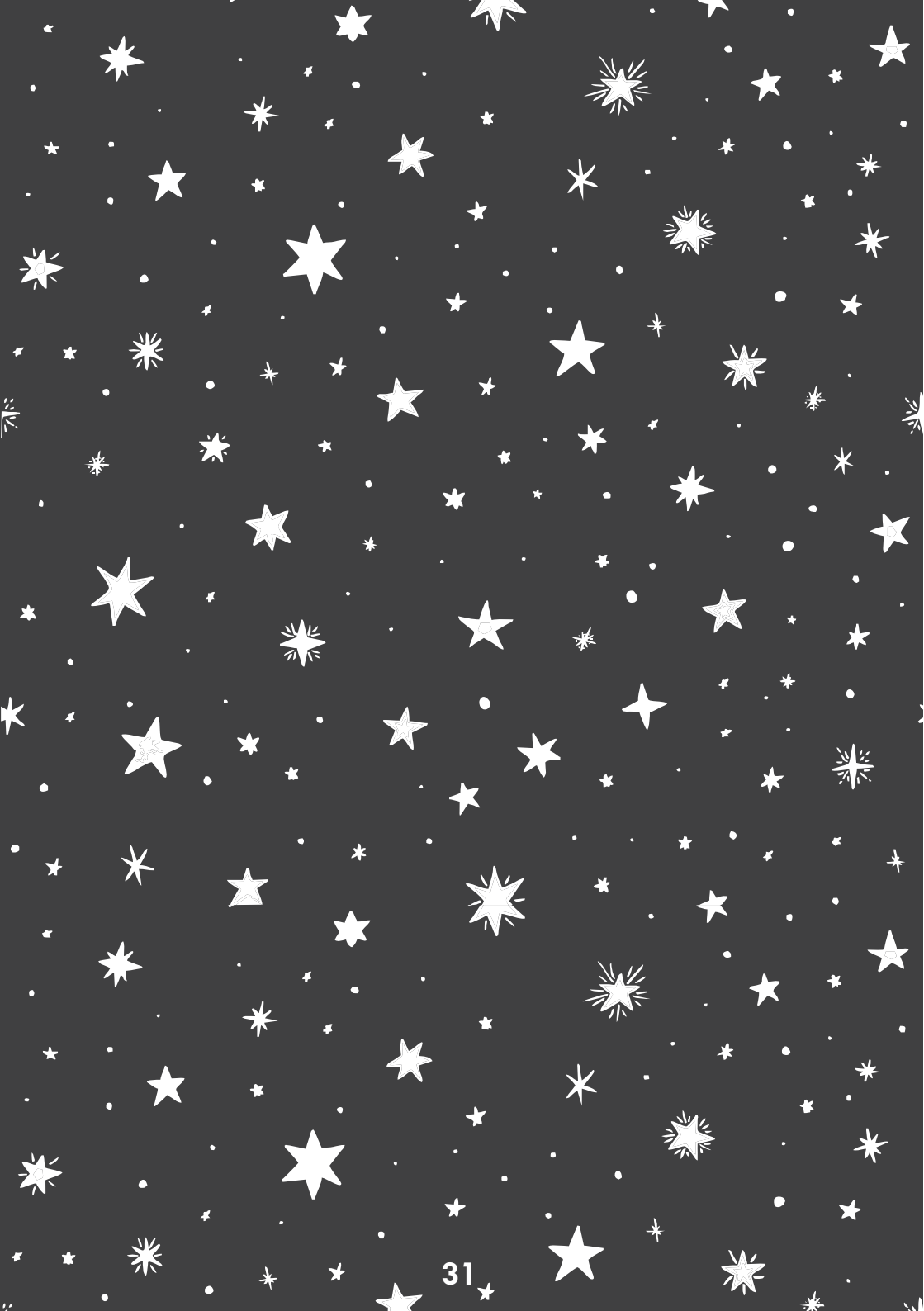
*I decided to change.
I want to become a female,
completely.*

*Routine medicine taking is the key
to success. My menstruation
becomes regular so I am able
to bring my child into
this world.*

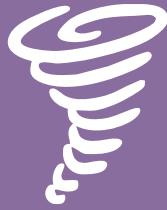
*I am so grateful for
my husband who supports me
and my baby daughter who
strengthens
my spirit to continue facing my life
with zeal.*

Warmest greetings from me,

Bintang







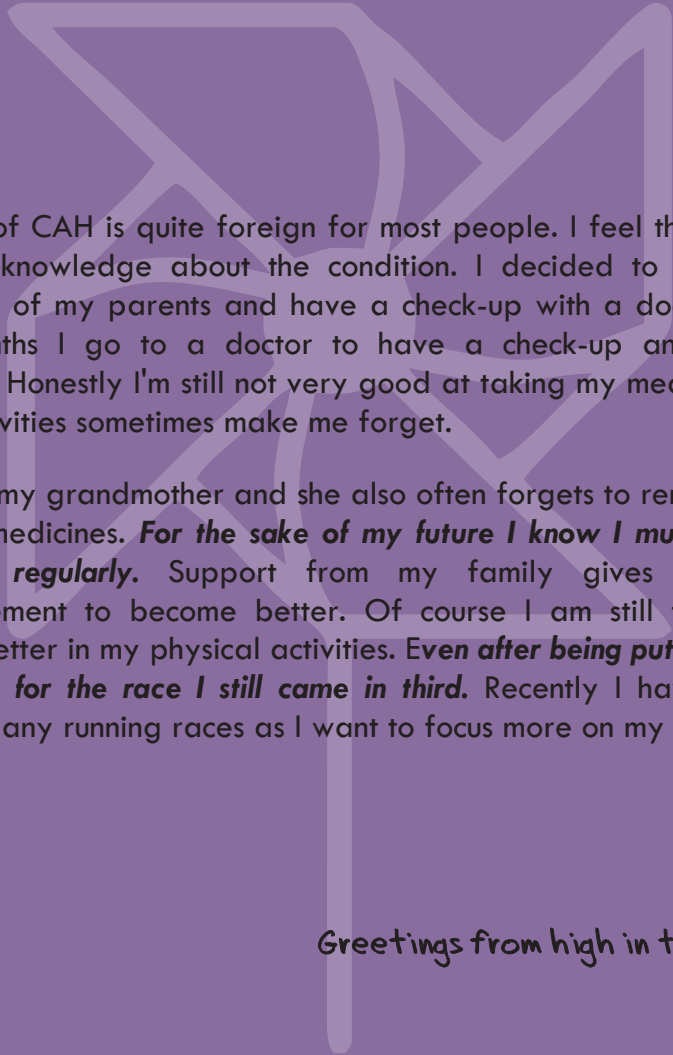
I AM A RUNNER

My name is Angin,

My age is 12 and I'm in second grade in junior high school. My voice is deep, my skin is dark, and coarse hair grows on my face, legs and armpits. Am I a boy? I'm not sure I'm a girl. Although physically I'm more like a boy, even my chest is like a boy's, I consider myself a girl.

I actually feel lucky to be physically like a boy because I am stronger than other girls my age. I can channel this difference into my hobbies because I like physical activities. I became a runner. Already I have run in a few races and won. I hadn't thought much about my appearance until one day my grandmother suggested that my father take me to get a check-up.



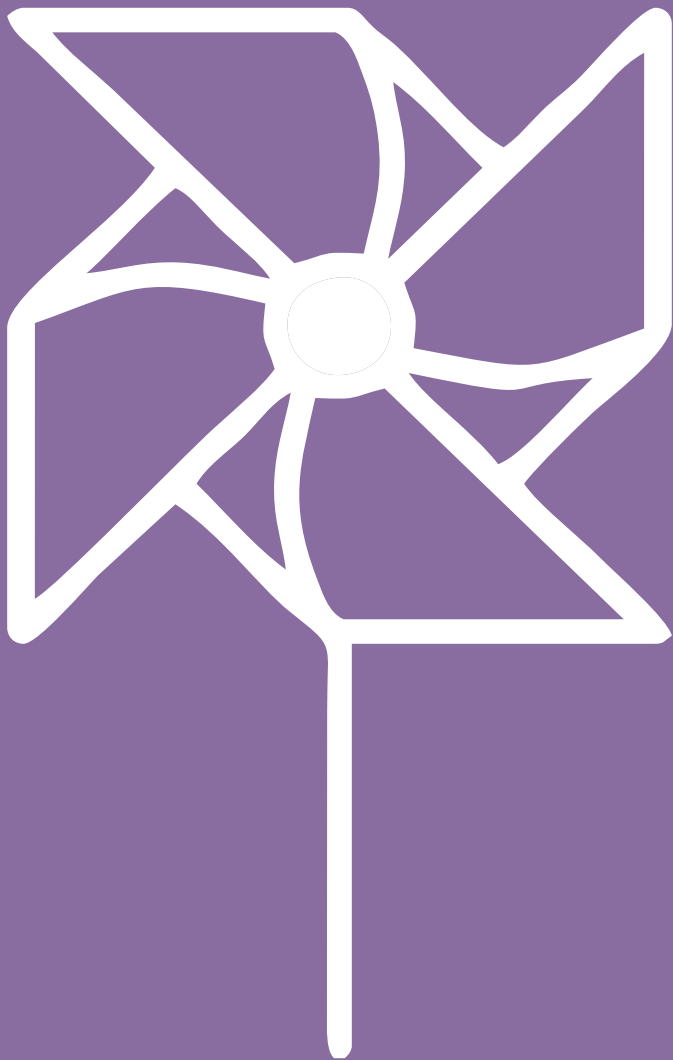


The idea of CAH is quite foreign for most people. I feel that there is not much knowledge about the condition. I decided to follow the suggestion of my parents and have a check-up with a doctor. Every three months I go to a doctor to have a check-up and get my medicines. Honestly I'm still not very good at taking my medicines. My school activities sometimes make me forget.

I live with my grandmother and she also often forgets to remind me to take my medicines. ***For the sake of my future I know I must take my medicines regularly.*** Support from my family gives me more encouragement to become better. Of course I am still training to become better in my physical activities. ***Even after being put in a higher age group for the race I still came in third.*** Recently I haven't been entering many running races as I want to focus more on my studies.

Greetings from high in the trees,

Angin




my diary

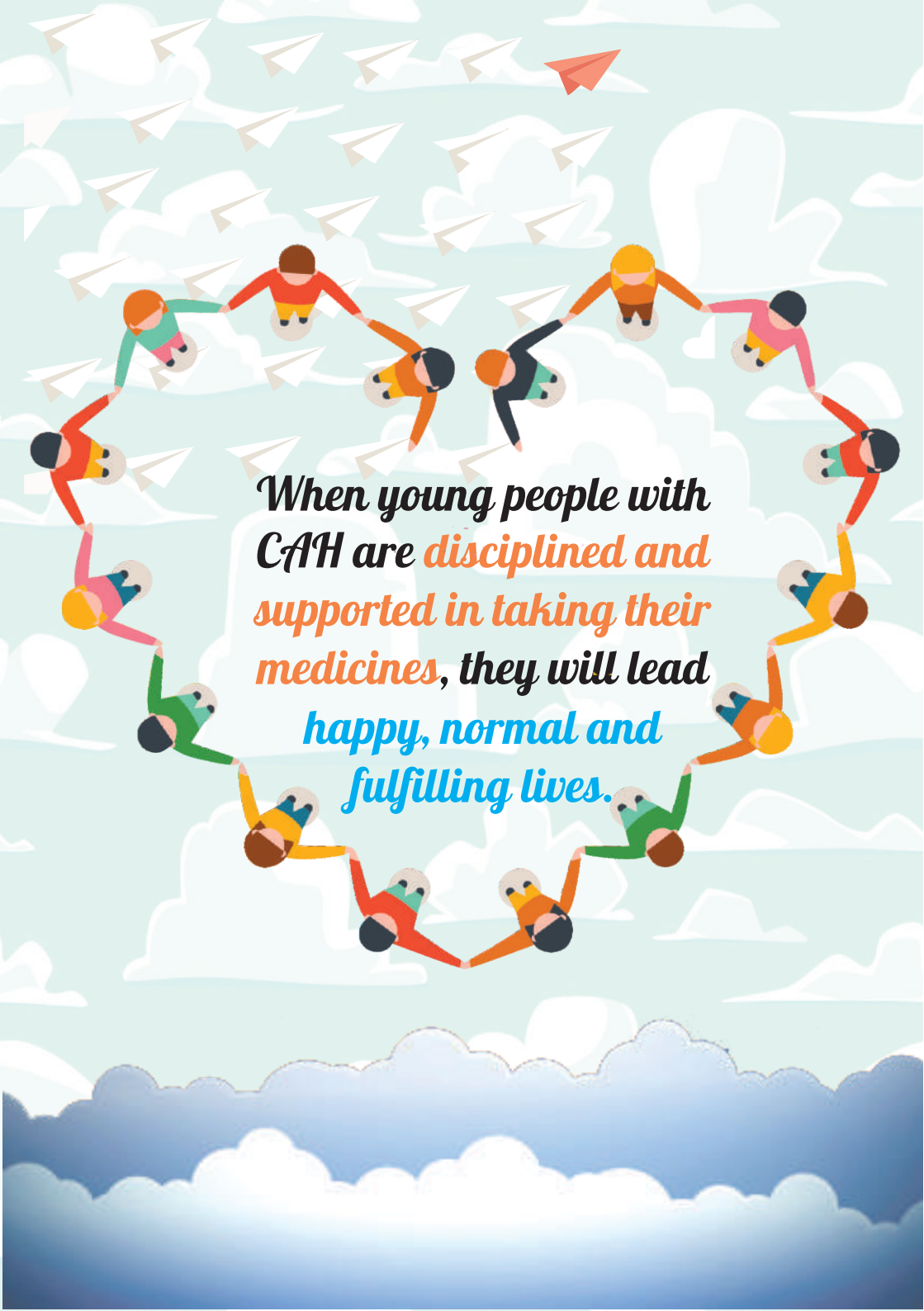
Date _____ No. _____

My smile has returned. I am cheerful when I'm with others. Gratefulness and self-belief have returned to accompany my every step. I do what I must with a sense of patience so I can go back to living the life I should. There is no sorrow or disappointment. My struggle paid off. I feel centred and ready to face the world. All of these struggles are lessons which I will not forget.

I hope that I can inspire those around me.

Semarang, 19 December 2016



An illustration of a group of 15 diverse children holding hands in a circle, floating in a sky filled with white clouds and numerous white paper airplanes. One red paper airplane is prominent at the top. The children are wearing various colorful clothing. The text is centered within the circle of children.

*When young people with
CAH are **disciplined and
supported in taking their
medicines**, they will lead
**happy, normal and
fulfilling lives.***

My dreams



My goals

My Inspiration

My dreams



My goals

My Inspiration

ACKNOWLEDGEMENTS

We acknowledge collaboration with CLAN (Caring and Living as Neighbours) on the translation of this book into English, particularly the efforts of Joe Freeman and Fatima Idayeen, participating through the New Colombo Plan from Australian Department of Foreign Affairs and Trade, and Emma Santini, affiliated with Lehigh University (USA).



Maximising quality of life for children living with chronic health conditions in resource-poor countries through:

1. Access to affordable medication and equipment
2. Education, research and advocacy
3. Optimising medical management
4. Encouraging family support groups
5. Reducing poverty and promoting financial independence

so the children may grow to enjoy healthy, happy and fulfilling lives and know their neighbours care.



UNDIP PRESS
DIPONEGORO UNIVERSITY
SEMARANG