

Tā Ben Huaranga Pūtau Tō

He aratohu mā ngā tamariki ka whiwhi huaranga pūtau tō (SCT)



 leukaemia &
blood cancer
new zealand

our mission is to care, our vision is to cure

Mōu ake

Nōu anō tēnei pukaiti hei āwhina kia mātau koe he aha i matea e koe he huaranga pūtau tō (SCT), hei whakamārama anō i ngā mea ka pā pea ki a koe. E matea ana pea e koe te huaranga pūtau tō nō te mea kāore pea i te mahi tika ētahi pūtau toto ōu.



taku ingoa tuatahi:

.....

taku pakeke:

.....

taku hōhipera:

.....

rā o te huaranga:

.....

Ngā mihi ki a:



Tā Ben Huaranga Pūtau Tō

He mea whakaputa te putanga tuatahi nā te Komiti
Whakaputanga o te Rōpū o ngā Tamariki Mate i te
Pukupuku me te Pukupuku Pūtau Toto Mā

Nā Julie Guest i
whakatikatika.

He mea whakaahua
nā Christine Sharp.



our mission is to care, our vision is to cure

He aha rā te pūtau tō?

Ka hangā e ngā pūtau tō ō pūtau toto katoa i roto i te wheketere ka huaina nei ko te roro kōiwi. Kāore i te tika te hanga a te wheketere i ētahi o ō pūtau toto, ā, mā te te huaranga pūtau tō e āwhina kia pai ake pea te mahi a te wheketere.



Tūtaki ki a Ben

Ko Ben tēnei. Māna e kōrero ki a
koe he pēhea te āhua o te whiwhi
huaranga pūtau tō.



Ngā



Ka tīmata a Ben mā te kōrero ki a koe i ngā mea ka tūpono i mua i te huaranga.

Tērā pea ka maha ō whakamātautau rerekē i mua i te huaranga, kia tino mōhio ai kei te pai tō tinana.

Me rapa ko ēhea ō ēnei hakamātautau, inenga rānei e hiahiatia e koe, otirā, mēnā ka hiahiatia kia mahia tētahi atu mea ki a koe.

**Whakaahua
whakaroto**

**Ngā whakamātautau
toto**

Tiro tiro niho

Karapa manawa

**Ngā whakamātautau
ngāngā**

**Whakamātautau
Tākihi**

Tō Roa

Tō Taumaha

Ngā kaimahi i te hōhipera

Ka tūtaki a Ben ki ngā tāngata hōu tokomaha i te wā o tōna huaranga pūtau tō. Anei anō he rārangi o ngā tāngata rerekē tērā pea e tūtaki koe.

Me tuhi pea e koe ngā ingoa kia maumaharatia,
me tātuhi rānei he pikitia o Rātou.

Ngā tākuta huaranga

Ngā tapuhi huaranga

Mātanga Kai

Ngā Kaiako

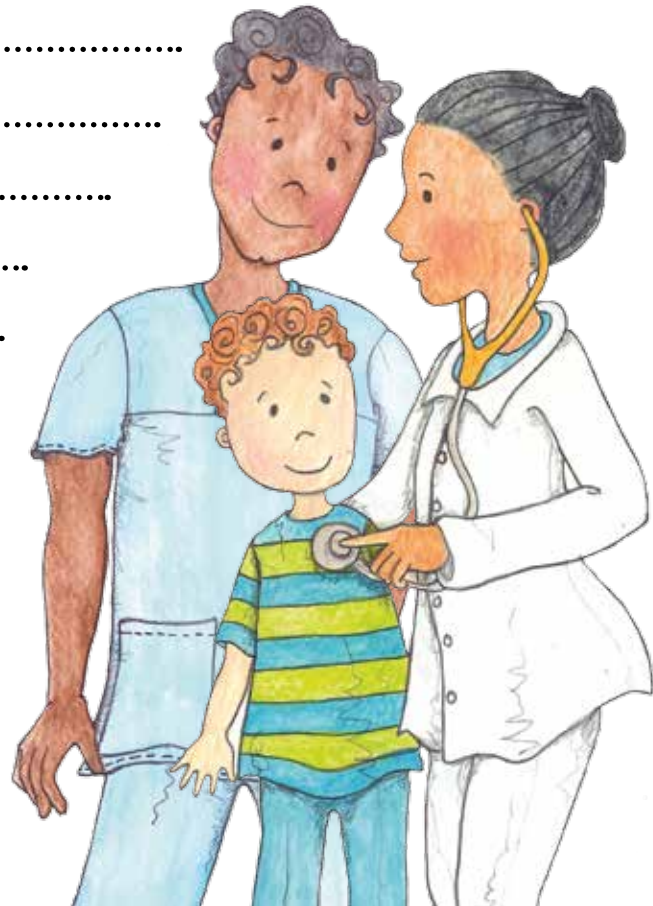
Kaimahi ā-lwi

Kaihaumanu tinana /
Kaihaumanu whakamahi tinana

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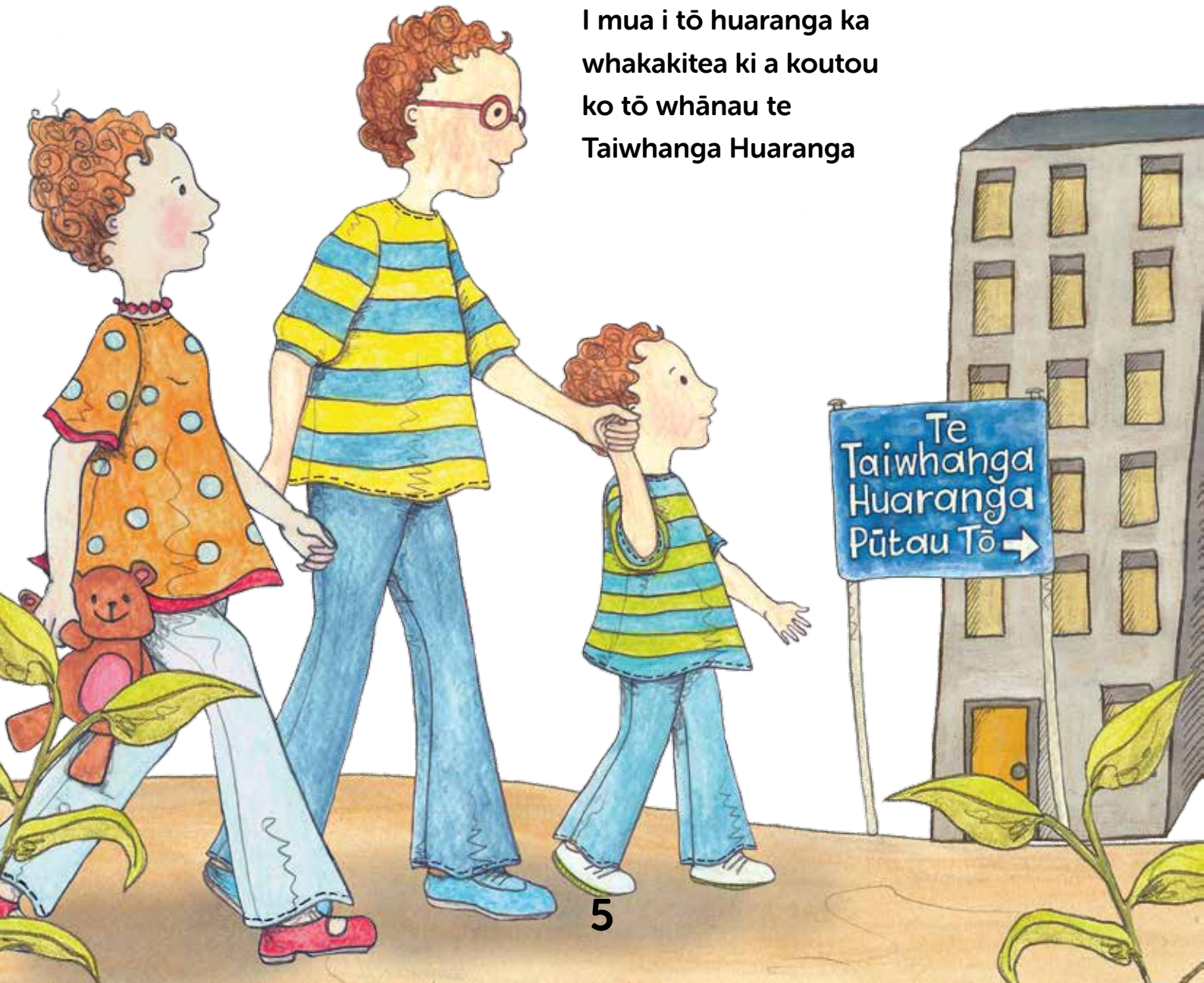
Kaiwhakamātau
hinengaro

Kaiāwhina hauora /
Ngā Kaitahitahi



Te Taiwhanga Huaranga Pūtau Tō

I mua i tō huaranga ka
whakakitea ki a koutou
ko tō whānau te
Taiwhanga Huaranga



He mea tauhou te haere mai ki te hōhipera mō tō huaranga pūtau tō. Ka noho pea koe i te hōhipera mō te ono wiki, roa ake pea. Ka pēnei pea he wā roa tēnei otirā kei te pīrangi pea koe kia mōhio ki te aha ka tūpono, ka pēhea hoki tōu kare ā-roto.

He rerekē te āhua o ngā tāngata katoa mō te haere ki te hōhipera. Kei te hiamō pea koe, kei te āwangawanga, kei te koa, matakū, pōuri, riri, wehi, māharahara rānei? Tērā pea ka āwhina te kōrerorero mō ēnei kare ā-roto.

Ina mahia tō huaranga me haere koe ki tētahi rūma ko tō kotahi hei rūma moe mōu anake. Ka rongō pea koe i ētahi e kī ana he 'noho motu kē' tēnei, engari ka haere tonu tō whānau me ō hoa ki a koe i reira.



Maimoatanga o Ben



I mua i te
tīmatanga o te
maimoatanga mō te huaranga,
i haere au ki te taiwhanga
poka kia homai ai he
ngongo rongoā.

Ko te ngongo rongoā, ka huaina i ētahi wā ko
te 'ngongo o Hickman', ka whakamahia mō
ngā whakamātautau toto me te hoatu i ngā
maimoatanga e matea ana e koe.

Ki te kāhore tāu ngongo rongoā, me hoatu
tētahi ki a koe i mua i tō huaranga. Ka mau koe
i tērā mō ētahi marama, heoi ka āhei tonu
koe te tākaro me te haere ki te kura,
kāhore ia te kaukau.

I mua i te mahinga i tō huaranga, ka hoatu ki a koe ētahi maimoatanga e takatū ai tō tinana mō te huaranga. Mō ētahi tamariki ka rua noa iho ngā rā maimoatanga, mō ētahi atu ka rua wiki rā anō. Kei roto pea i tēnei maimoatanga ko te haumanu-ā-matū, te haumanu-ā-iraruke rānei, ēnei mea e rua rānei.

He maimoatanga motuhake te haumanu-ā-matū me te rongoā. Ka hoatu ēnei rongoā mā tō ngongo rongoā, mā tō waha rānei. Ko tōna mahi nui ko te patu i ngā pūtau i roto i tō tinana kāore i te mahi tōtika, ko te whakamate hoki i ōu pūtau tō ake me kua ēnei e whawhai ki ngā pūtau tō hōu ina hoatu ēnei ki a koe.

I kite a Ben he pai tonu te whakaaro ki te haumanu-ā-matū hei hōia i tētahi ope tauā.



Haumanu-ā-iraruke

Kāore e hoatu te haumanu-ā-iraruke ki ngā tamariki katoa e whiwhi huaranga pūtau tō. He momo X-ray motuhake te haumanu-ā-iraruke ka patu i ngā pūtau i tō tinana kāore e tōtika te mahi, ka patu hoki i ōu ake pūtau tō.

Kāore e mamae te haumanu-ā-iraruke engari he tino hira tonu kia takoto hū rawa koe i roto i tēnei maimoatanga. Ka haere te haumanu-ā-iraruke mō te 20 meneti pea. He rerekē te haruru o te mīhini whakaahua whakaroto. Kāore e āhei tētahi atu te noho i te rūma i a koe e whiwhi ana te haumanu-ā-iraruke, heoi ka āhei rātou te kite me te rongoi i a koe i tētahi pouaka whakaata motuhake.

Me whiwhi rawa i a koe te haumanu-ā-iraruke i mua i tō huaranga?

I kite a Ben i haere te wā i a ia e mātakitaki ana i tana tino whitiāhua, i a ia e whakarongo ana rānei ki āna tino waiata.

Me whakaaro ki te DVD, te puoro rānei e mauria atu e koe.



Te Rā Huaranga

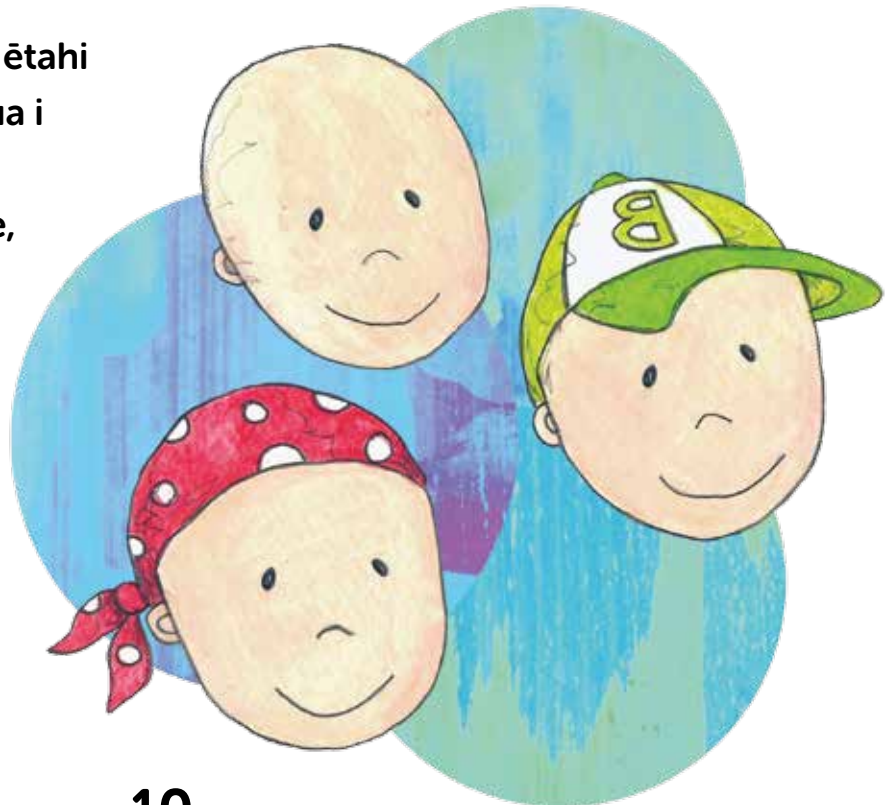
Ka mutu tō haumanu-ā-matū, haumanu-ā-iraruke hoki/rānei, ka hoatu ki a koe ngā pūtau tō mā te Hickman, te ngongo rongoā. Ka huaina tō rā huaranga ko te 'rā 0' e ngā tākuta me ngā tapuhi.

Mō te rua wiki i muri i te haumanu ā-matū me te haumanu ā-iraruke ka tīmata pea ō makawe te makere mai. Kāore e mamae tēnei.

Ka makere hoki pea ō tukemata me ō kamo.

Ka tapahia ngā makawe o ētahi tamariki kia tino poto i mua i te huaranga. Ka mau kape motuhake ētahi atu, pōtae, hururua rānei kia tipu anō ō rātou makawe.

Ka tipu anō he makawe hōu i muri i te 3 ki te 6 marama.



I tiaki a Ben i tōna waha

Tērā pea ka āhua māuiui koe i muri i te haumanu ā-matū, haumanu ā-iraruke rānei. Ka mutu tō maimoatanga ka haere tonu pea tēnei māuiuitanga, nā ētahi atu rongoā pea, raru rānei. Ka hoatu rongoā pea ngā tapuhi ki a koe mā te waha, mā te ngongo rongoā rānei, kia mutu te māuiuitanga.



He mea nui kia kōrero koe ki ngā tapuhi ina māuiui koe, kia āwhina rātou i a koe.

I kite a Ben he pai tonu te momi pūtoru tio, ngā unu auau paku rānei o te wai.

Ka mamae pea tō waha i te haumanu ā-matū me te haumanu ā-iraruke i te mea ka patua ngā pūtau pai me ngā pūtau kino. Ko te tikanga pai rawa hei āwhina i tēnei raru, ko te tiaki i tō waha kia mā.



E hiahia ana mātou kia horoi koe i ō niho ki te parahi ngohengohe me te paniniho, te horoi waha rānei kia 3-4 ngā wā ia rā. Ki te mamae rawa tō waha mō tēnei, ka taea te whakamahi i ngā hautai motuhake.

Ka tono pea ngā tākuta me ngā tapuhi kia titiro ki roto ki tō waha ia rā.

He hira tonu kia kōrero koe ki a rātou he pēhea tō waha, inā tonu kei te mamae, kia āwhina ai rātou i te rongu mamae o tō waha mā te hoatu rongoa patu mamae ki a koe.

I kite a Ben i pai tonu te momi i ngā rare tio, te wai tio rānei i te wā i mamae tōna waha. I ngā wā i tino mamae tōna waha kāore i pai a Ben ki te kai, ki te inu rānei. Heoi i pai haere ake te waha o Ben.

Te ngongo o Ben

He ngongo tā Ben i roto i tōna ihu tae iho ki tōna puku. Kāore i tino pai te whakaurunga o te ngongo, heoi nā reira i mutu ai ngā tono a te whānau kia kai, kia inu rānei. Nā te ngongo i kainga e Ben te whāngai miraka motuhake i āwhina kia whai kaha tonu ia i roto i tana huaranga. Ka whakamahia hoki te ngongo mō ngā rongoa i tino tautoko i a Ben.

Ina tino māuiui koe i te whāngai miraka, kei reira he whāngai motuhake anō (TPN) ka hoatu mā tō ngongo rongoa.



Te moemanga motuhake o Ben

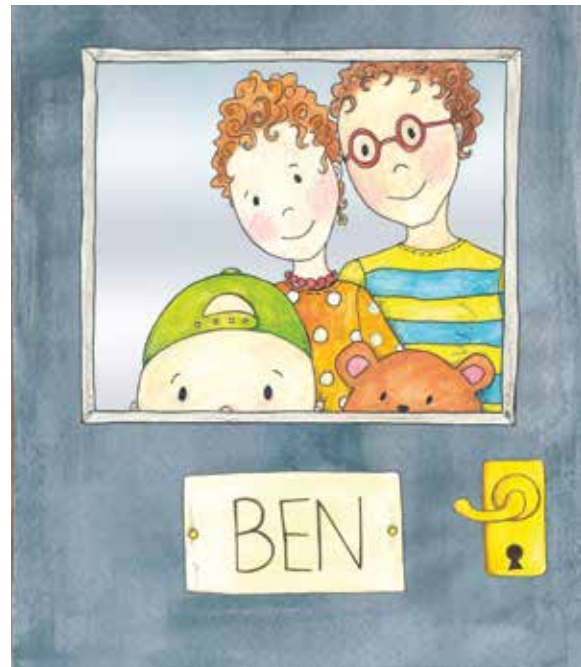
Ka whakangaromia ō pūtau tō tawhito e tō maimoatanga. Ko tōna tikanga kāore e tino nui ō pūtau mā ka toe.

He tino hira ngā pūtau mā hei pare i tō tinana ki te mate.

Ko te take e whiwahi rūma motuhake koe i te hōhipera mahue kē te noho tahi me ērā atu tamariki, ko te whakangungu i a koe i te mate.

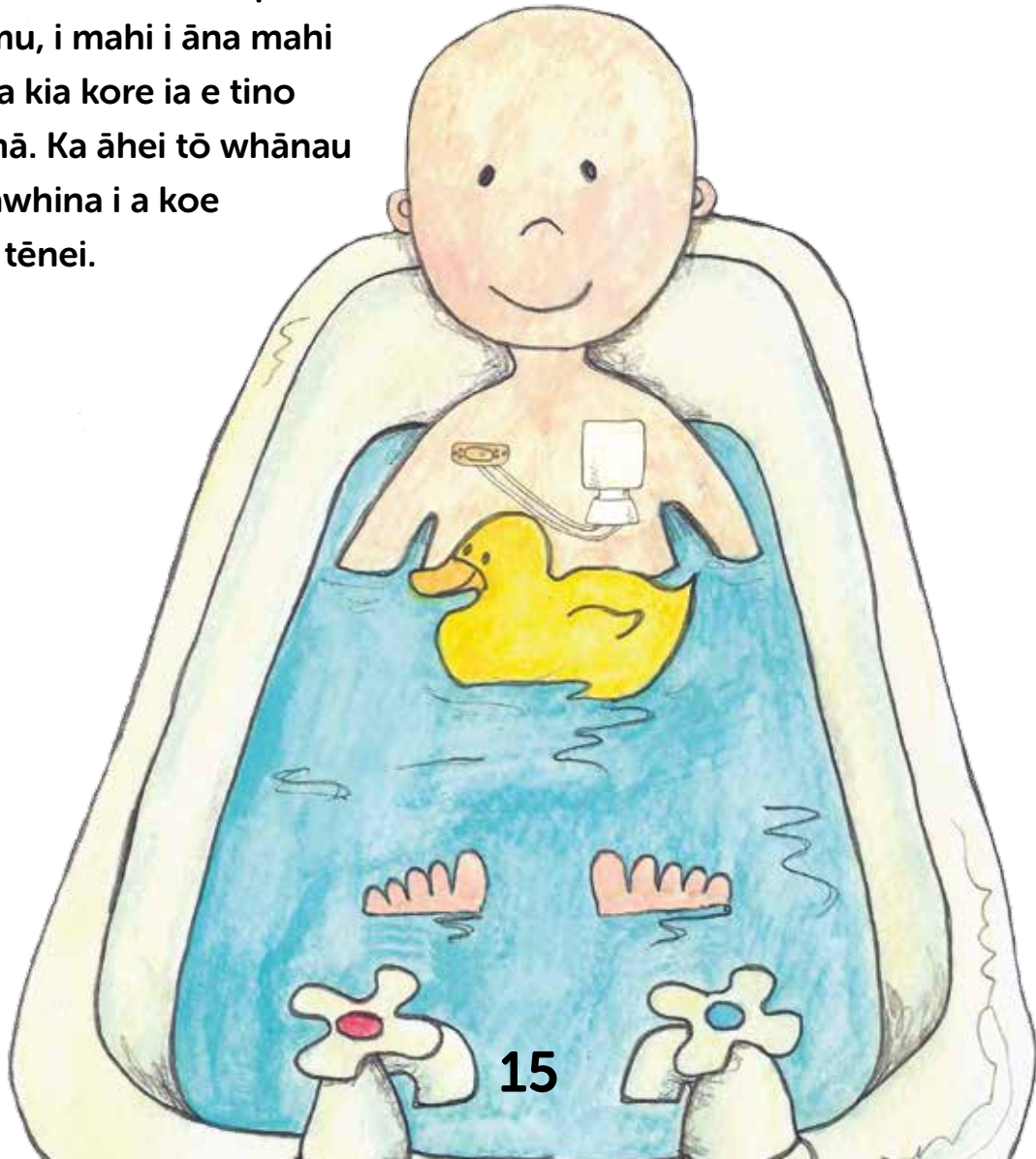
Ka taea e tētahi o tō whānau te noho tata hei tiaki i a koe, ka taea anō he manuhiri engari me hauora tonu rātou.

Tērā e pai pea koe ki te whakapā atu ki ō tungāne, ō tuāhine rānei me ō hoa kura mā te waea, te reta, te kuputuhi, te ipurangi rānei.



Tō Ben wā kaukau

He nui te wā i pau i a
Ben i te rorohiko, i purei
kēmu, i mahi i āna mahi
kura kia kore ia e tino
hōhā. Ka āhei tō whānau
te āwhina i a koe
me tēnei.

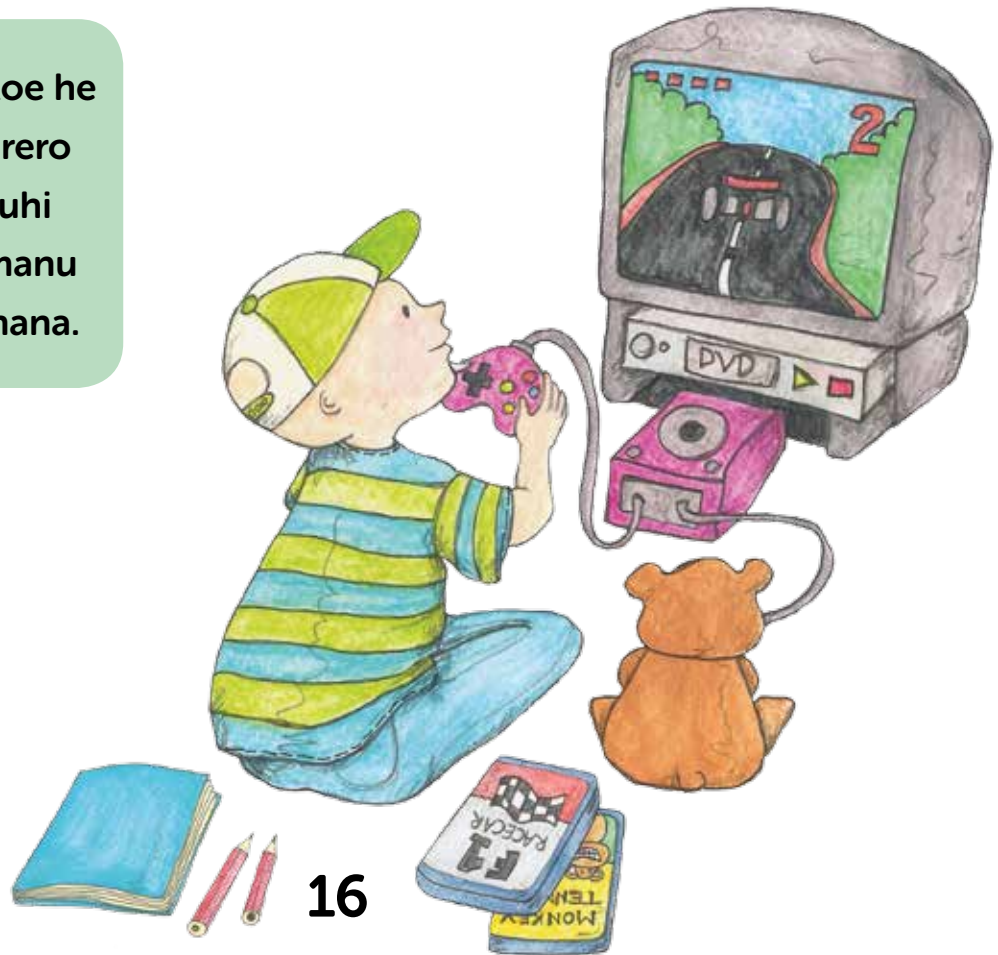


I aha rā a Ben

Ka tonongia koe kia horoi, kia uwhiuwhi, kia kaukau rānei ia rā, me te whakamau kākahu mā. Ka taea e tō whānau te āwhina i a koe mō tēnei.

Kua āta whakaritea rānei e koe tāu e aha ai kia kaua e hōhā rawa?

Me tuhi pea e koe he rārangi hei kōrero māu ki ō tapuhi me te kaihaumanu whakamahi tinana.

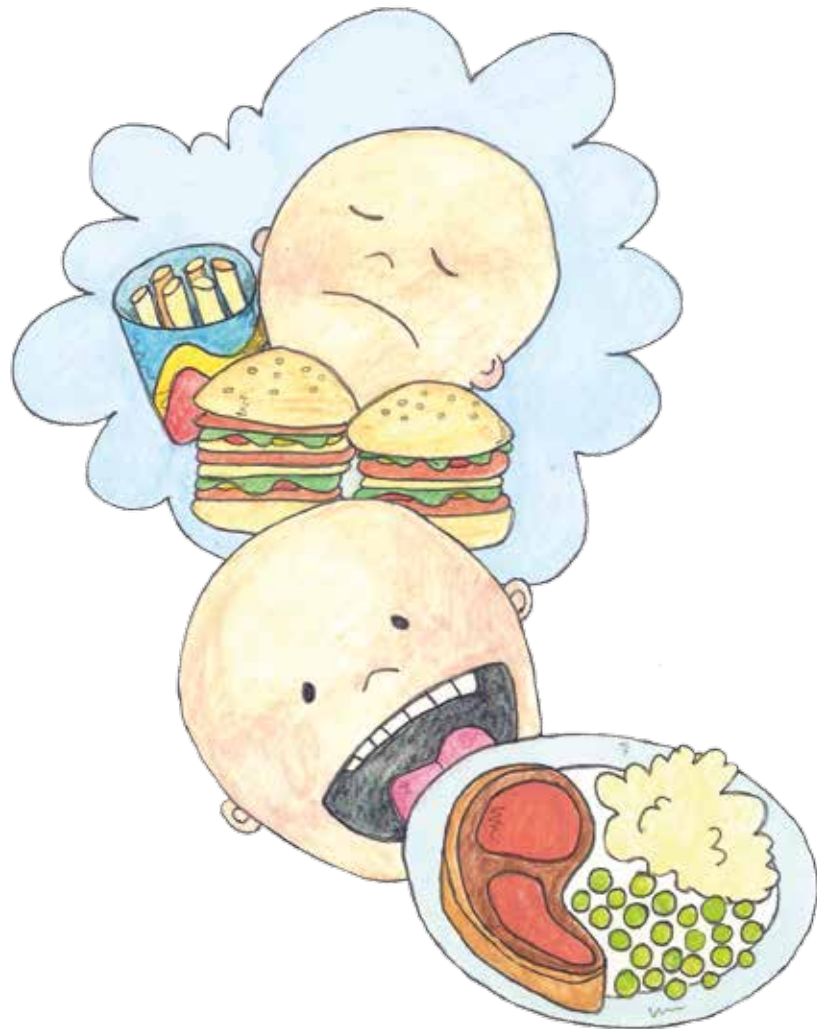


I kai a Ben i te aha

Kāore pea koe e whakaaetia
kia kai i ētahi o āu tino kai mō
tētahi wā, i te mea ka mamae
pea tō puku, ka mate rānei koe i
te tororere.

Mahia he rārangi o ngā kai
e pai koe ki te kai kia āhei tō
tapuhi te kōrero ki a koe mō
ngā kai ka taea, kāore e taea
rānei i te wā o tō huaranga.

Kāore koe e whakaaetia kia kai
i te kiri huarākau, te tōhua hēki
waiwai rānei.



I rongo anō a Ben ki te pai

Ina tīmata ō pūtau tō hōu te mahi ka tīmata anō koe ki te haere atu i tō rūma motuhake.

Ka mōhio ngā tapuhi me ngā tākuta ina rite koe mō tēnei mā te tiro tiro i tō kaute toto.

Ka tino hiamō a Ben i te meatanga ki a ia e āhei ana ia te haere atu i tōna rūma. Ka āhua matakū hoki ia, kua maha hoki ngā wiki i noho motu kē ia.

Me noho motu kē ētahi tamariki he roa ake i tēnei nā tētahi mate.

I āhei a Ben te takatū āiane mō te hoki ki te kāinga.



Ngā Rongoā



Ina tae koe ki te kāinga me kai koe i ētahi rongoā. Ko te tikanga, māu e kōwhiri i waenga i te pire, i te unu rānei, nā reira me tino ui atu ki te kore e mea rātou māu e whiriwhiri.

I kite a Ben he māmā ake ētahi rongoā te kai tahi me tōna tino unu, otirā mā te ngote rare i muri ake i ngaro ai te tāwara.

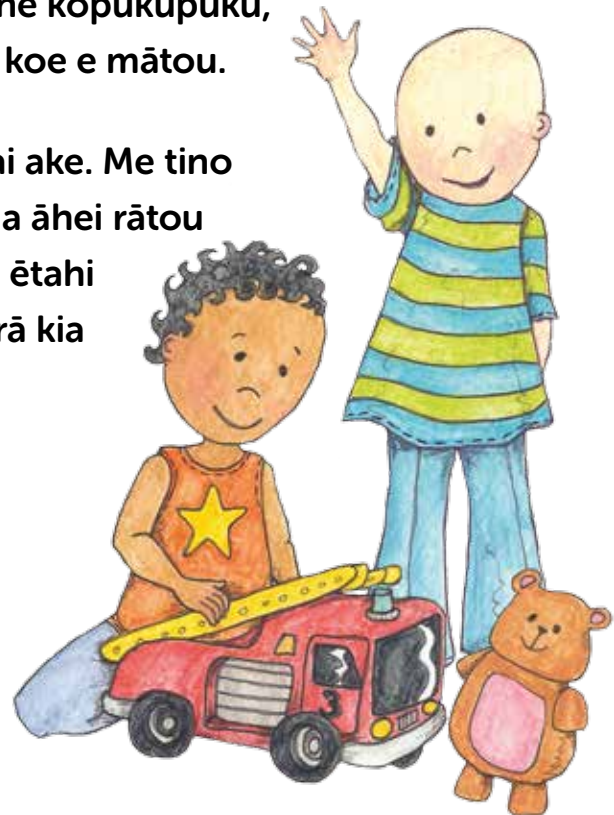
Ki te mau tonu te ngongo i tō ihu hei āwhina ki te whāngai i a koe, ka taea tēnā te whakamahi hoki mō ō rongoā.

Ngā haere hōhipera a Ben

Nō te hokinga o Ben ki te kāinga ka tahi, ka rua rānei āna hokinga ki te hōhipera i ia wiki, kia tangohia he toto kia mōhio ai i te mahi ngā rongoā. I pai tonu a Ben te hoki ki te hōhipera, i pai hoki ia kia kite anō i ngā tākuta me ngā tapuhi.

Ina hoki mai koe ki te hōhipera, ka tirohia e mātou tōu kiri kia mōhio ai kāhore he ira, he wāhi māeneene rānei. Ka whawhai tonu ō pūtau tō hōu ki tō tinana i ētahi wā, nā ka puta ai pea he kōpukupuku, he puku mate rānei, nā reira me tiro tiro tonu koe e mātou.

Tērā koe e hiahia rongoā anō mō tēnei kia pai ake. Me tino kōrero koe ki tō whānau ki te raruraru koe, kia āhei rātou te kawē i a koe ki te hōhipera kia tiro tirohia. I ētahi wā me hoki pea koe ki te hōhipera mō ētahi rā kia whakatikaia te raruraru.



Te puta mai i te hōhipera

Ina puta koe i te hōhipera kia tino tūpato kei hopu i a koe ētahi moroiti tahumaero. Hei te tīmatanga me noho koe i te kāinga, kia ruarua hoki ngā hoa toro mai. Ina haere mai ngā hoa he mea nui kia hauora tonu rātou, kāhore rā he mate. Ka kōrero ngā tapuhi ki a koe mō tēnei.

Kia kaua koe e haere ki ngā toa, ki ngā wāhi e nui ana te tangata, engari ka āhei te haere i waho ki te hau mata, te hīkoi poto rānei i te papa tākaro ina whai kaha koe.

Kāore pea koe e āhei te hoki ki te kura mō ētahi marama, engari ka āhei ō mātua te whakarite kē kia tuku mahi kura ō kaiako ki te kāinga.





Ka ngenge hoki pea koe i te nuinga o te wā, inā tonu mehemea i whiwhi haumanu iraruke koe. Ko te tikanga tēnei, otirā ka piki haere tō kaha, ā, he paku nui ake ngā mea ka taea e koe ia rā.

Kaua e āwangawanga ina hiamoe koe, ina pai rānei kia whakangā i te awatea. Ina kaha rawa ō pūtau tō hōu ka āhei koe te hoki ki te kura. I te tuatahi, me torutoru noa pea ngā hāora e haere koe, he rā haurua rānei i te mea ka ngenge tonu pea koe. Kaua e māharahara mō tēnei.

Ka tipu anō ngā makawe o Ben

I tīmata ngā makawe o Ben
ki te tipu anō i ētahi marama
i muri i tana huaranga.

I ētahi wā, ka āhua parauri
ake, ka mā ake, ka hūmenge
ake rānei ngā makawe ina
tipu anō.



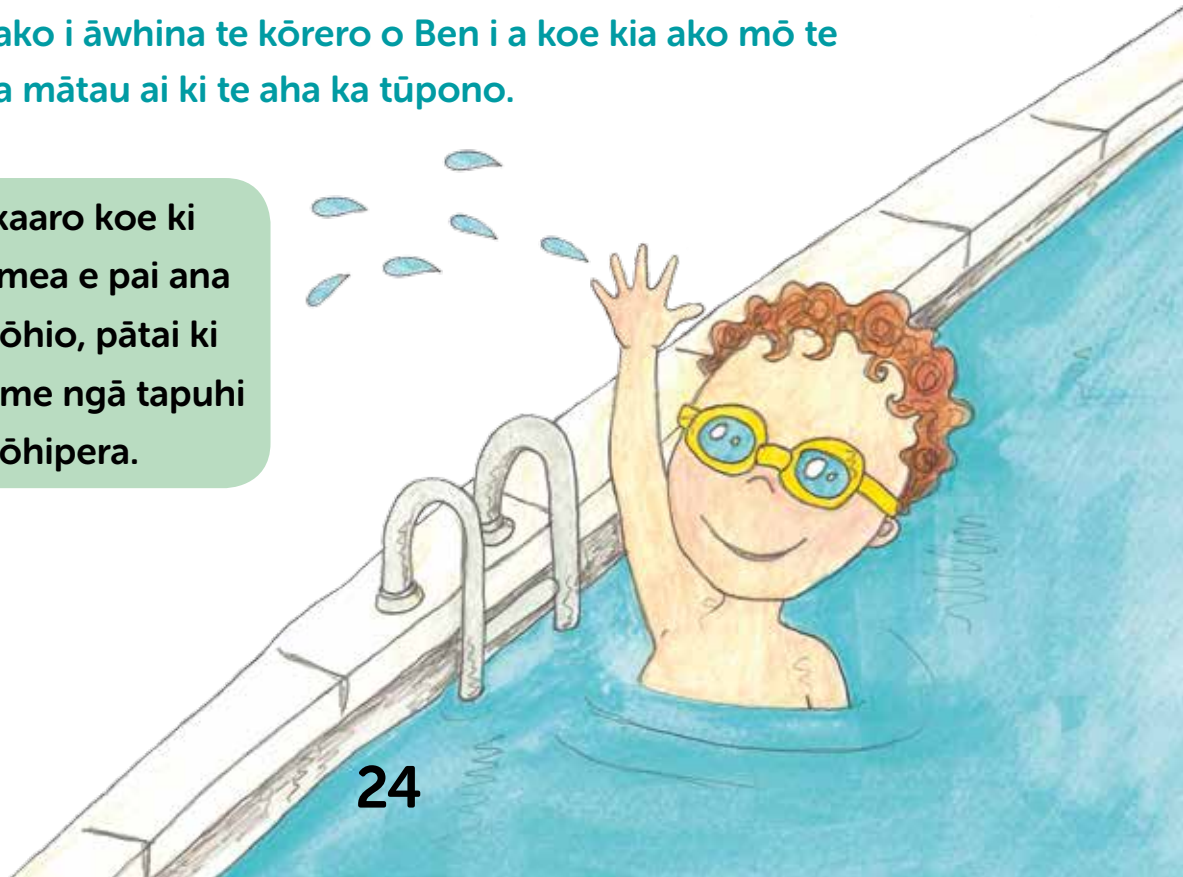
Ngā haere hōhipera a Ben

Nō te mutunga o te hiahia a Ben ki ngā whakamātautau toto, ki te rongoā rānei, kāore tonu i pīrangitia tana ngongo rongoā. Ka pēnei i te 3 ki te 6 marama pea i muri i tana huaranga, ā, i tangohia tana ngongo rongoā. Kātahi a Ben i āhei te haere ki te kaukau, kia hōhonu ake anō tōna kaukau!

Kāore hoki i rite tonu te haere a Ben ki te whare hauora.

Ko te tūmanako i āwhina te kōrero o Ben i a koe kia ako mō te huaranga, kia mātau ai ki te aha ka tūpono.

Ina whakaaro koe ki tētahi atu mea e pai ana koe kia mōhio, pātai ki ngā tākuta me ngā tapuhi i tō hōhipera.



Te tikanga o ēnei kupu

Ka rongō pea koe i ngā kupu hōu maha i a koe i te hōhipera.
Kei raro nei ētahi o ngā kupu matua me te tikanga. Ki te ruarua
koe mō ētahi atu, me pātai noa ki tō tākuta, tō tapuhi rānei.

REHU ĀRAI MAMAE

Ina hoatu rongōā ngā tākuta ki a koe hei whakamoe i a koe i te pokanga,
kia kore ai koe e rongō i te mamae.

WHAKAMĀTAUTAU TOTO

Ina tirohia he tauira iti o ōu toto kia kite e hia ngā pūtau whero,
ngā pūtau mā me ngā mōtepe.

MATE PUKUPUKU

Ina tino rerekē (kino) ngā pūtau i roto i tō tinana, ā, ka tipu tonu,
ka tipu tonu, he mea herekore.

HAUMANU Ā-MATŪ

He ranunga o ngā rongōā rerekē e maimoa ana i te mate pukupuku.

KARAPA CT

He whakaahua whakaroto e titiro ai te tākuta ki roto i tō tinana ki ō whēkau katoa
Me takoto hū rawa koe.

Te tikanga o ēnei kupu

MĀTANGA TOTO

He tākuta ka tiaki i ngā tūroro me te tahumaero toto, pona taikiri rānei, me te raruraru o te toto, te pona taikiri rānei.

NGONGO HICKMAN

Ka whakaurua i raro i te rehu ārai mamae he ngongo kotahi, ngā ngongo e rua rānei, ka puta te pito i te poka iti i te kiri o tō poho.

PUKUPUKU TAIKIRI

Ko te mate pukupuku i te pūnaha taikiri.

NGĀ PONA TAIKIRI

Te wāhi noho o ngā pūtau e whawhai i te mate me te tahumaero.

Ka rahi ake ngā pona taikiri ina whawhai i te mate me te tahumaero, kei te hanga hoki i ētahi pūtau anō.

KARAPA MRI

He karapa e whiwhi ai te tākuta i te pikitia mārāma o ngā mea e ahatia ana i roto i tō tinana. He nui pea tōna haruru, otirā, ahakoa kāore e mamae, tērā pea ka whiwhi koe ki te rehu whakamoe, te rongoā rānei hei whakapārore i a koe.

Te tikanga o ēnei kupu

KOREPŪTAUMĀ

Ina tata kore ō pūtau toto mā (ngā pūtau mā ka whawhai i te mate).

Ko te tikanga o te korepūtaumā ka nui ake tō mōrearea ka pāngia koe e te mate.

MĀTANGA MATE PUKUPUKU

He tākuta e maimoa ana i te tangata mate pukupuku.

KARAPA PET

He karapa anō e āhei ai te tākuta te kite i ngā mea e ahatia ana i roto i tō tinana! Ko ngā wāhi o te tinana kei reira te pukupuku pona taikiri ka kitea i te karapa hei wāhi mārāma.

NGONGO PICC

He ngongo kotahi, e rua rānei ka whakaurua ki roto i a koe i raro i te rehu whakamoe, e puta ai te pito i tētahi poka iti i te kiri o tō ringa.

NGONGOKAWE

He ngongo ka whakaurua i raro i te kiri tata ki te kēkē i a koe i raro i te rehu whakamoe, ka haere i raro i te kiri ki te uaua matua i te kakī. Ka hoatu he rongoā, ka tangohia rānei he toto, ka pania he 'kirīmi wana' ki te kiri e poki ana i te ngongokawe i te hāora kotahi i mua atu – kia kōpā taua wāhi me te kore e mamae ina uru te ngira.

RARURARU TŪPONO

Tētahi mea ka tūpono pea nā te maimoatanga, hei tauira, te rongo i te mate, te makawe makere iho rānei.



Ko Leukaemia & Blood Cancer New Zealand tētahi whakahaere ā-motu i Aotearoa i whakaihia ki te tautoko i ngā tūroro me ō rātou whānau e mate ana i te pukupuku toto, te pukupuku taikiri, te pukupuku roro kōiwi, me ngā mate toto pērā.

He rerekē te wheako o ngā whānau katoa; ehara i te mea ngāwari te ora i te pukupuku toto, mate toto rānei, engari kei a koe ētahi hoa tautoko.

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He mea whakaputa te putanga tuatahi nā te Children's Cancer and Leukaemia Group Publications Committee (UK), he mea whakatika nā Julie Guest. He mea whakarerekē e te Leukaemia Foundation of Australia me te tautoko a ngā mātanga mate toto me ngā tapuhi o Ahitereiria. Ngā mihi motuhake ki a Dr Michael Osborn, Bernadette O'Grady me Jill Shergold. E whakamihia nuitia ana e te Leukaemia Foundation te CCLG mō te whakaaetanga ki te whakarerekē me te whakaputa i tēnei pukaiti hei whakamahi i Ahitereiria.

Nā Christine Sharp ngā pikitia.

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**Ki te mea he pātai āu ki te ruarua rānei koe mō tētahi mea,
pātai ki tētahi o tō kapa maimoa,
whakapā rānei ki Leukaemia & Blood Cancer New Zealand.**

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